ALAN

Acute Leukemia Advocates Network

ALAN GLOBAL SUMMIT

#ALANSUMMIT

www.acuteleuk.org

willkommen
Sveiki atvyke
Mire se vini
valkomna
witamy
ngiyanemukela
benvenuti
Khushamdeed
SELAMAT DATANG
hoşgeldiniz
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Maligayang pagdating
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Tere tulemast
Mishto-avilian tu
laipni ludzam
Bem-vindos
Khair Raghly
mauya
benvenguts
failte
ekabo
Kenang ka kgotso
Murakaza neza

#ALANsummit

Find your buddy

- Go around the room and find your « half »
- Meet and greet!

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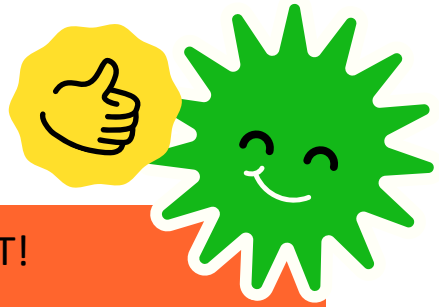
#ALANSUMMIT

INSPIRE, CONNECT, EDUCATE

TODAY'S AGENDA



1.30 PM	Find your buddy
2 PM	Welcome and opening
2.30 PM	Medical updates on acute leukemias
4 PM	Reconnect with your buddy
4.30PM	From experience to action
5.30 PM	Yoga with chair
7 PM	Dinner (on the rooftop)

DON'T FORGET!

- We do not expect anyone to be an observer - Everyone is welcome and encourage to participate
- Activities proposed during the breaks are optional
- Bad english is the official language

TO-DOS

- Be on time !
- Keep your badge on
- Mute your phone and switch off your computer

Tools to interact

- **WhatsApp community**
  - **General (for logistical questions)**

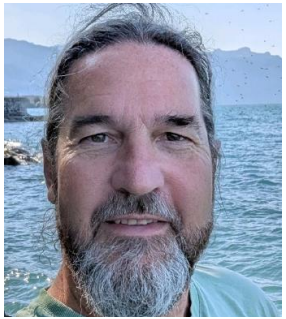
    https://chat.whatsapp.com/EYX3nJlPayi35h4PUheXoh
  - **#ALANsummit (for pictures)**

    https://chat.whatsapp.com/L4KC4FoSnn6LhA32Q6r6gJ
- **Consent for pictures**
- **Badge**

  Please wear it and make sure everyone can see it !

Important faces during the next days!

MARIEL
Moderator
Time keeper



ALASTAIR
Report writer

Samantha
Onsite logistics

Christine
Onsite logistics

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Thank You to Our Sponsors

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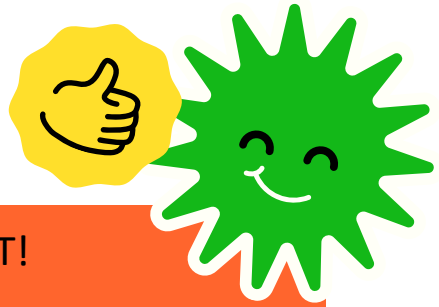
We would like to extend our sincerest thanks to the following sponsors for their invaluable support and partnership:

(YOUR) AGENDA

FRIDAY'S AGENDA



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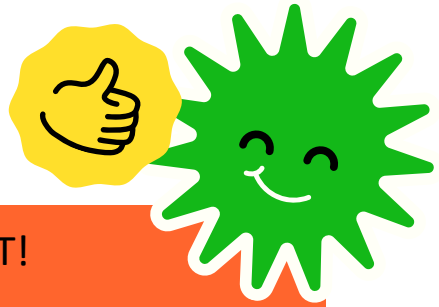
SATURDAY'S AGENDA



8.15 AM	Grounding
8.30 AM	Workshop: Advocacy in the acute setting
10 AM	May I borrow your buddy?
10.30 AM	Let's talk about data
11 AM	Turning insights into action
12.30 PM	Group photo
12.45 PM	Lunch

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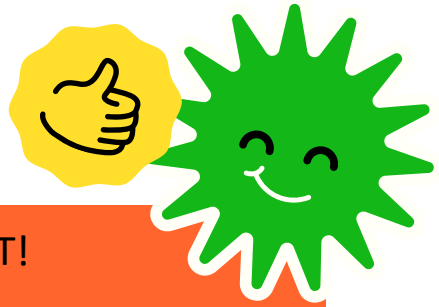

1.30 PM	From Data Collection to Advocacy
2.30 PM	Turning Insights into Access
3.30 PM	Marshmallow challenge
4 PM	Workshop: Barriers to access
5.30 PM	Yoga with chair
7 PM	Dinner (hotel)

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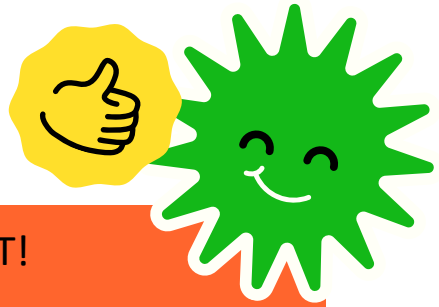
SUNDAY'S AGENDA



8.15 AM	Breathing / Mindfulness
8.30 AM	Access – Global Realities and Solutions
9.30 AM	Power in Partnership
10.30 AM	Buddy Check in
11 AM	Workshop: What to Advocate for Locally?
11.45 AM	Closing and goodbye
12.30 PM	Lunch and departures

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INTRODUCTIONS

WHAT IS ALAN

- ALAN is a global network of patient organisations focused on acute leukemias (AML, ALL, etc), hosted by the Leukemia Patient Advocates Foundation (LePAF).
- ALAN's mission is to improve patient outcomes by strengthening advocacy, sharing best practices, developing resources for patients and carers, raising awareness, and collaborating with stakeholders in policy, research, and healthcare

WHAT DO WE DO

- ALAN has a number of key activities:
  - developing patient information and specific support for patients with acute leukemias and their carers in all countries;
  - strengthening patient organisations by sharing best practices and providing toolkits in patient advocacy;
  - creating awareness about acute leukemias and how to better support leukemia patients;
  - advocating for better treatment, care & access to healthcare services;
  - collaborating with other initiatives and stakeholders with similar goals.

- Check the ALAN website: www.acuteleuk.org

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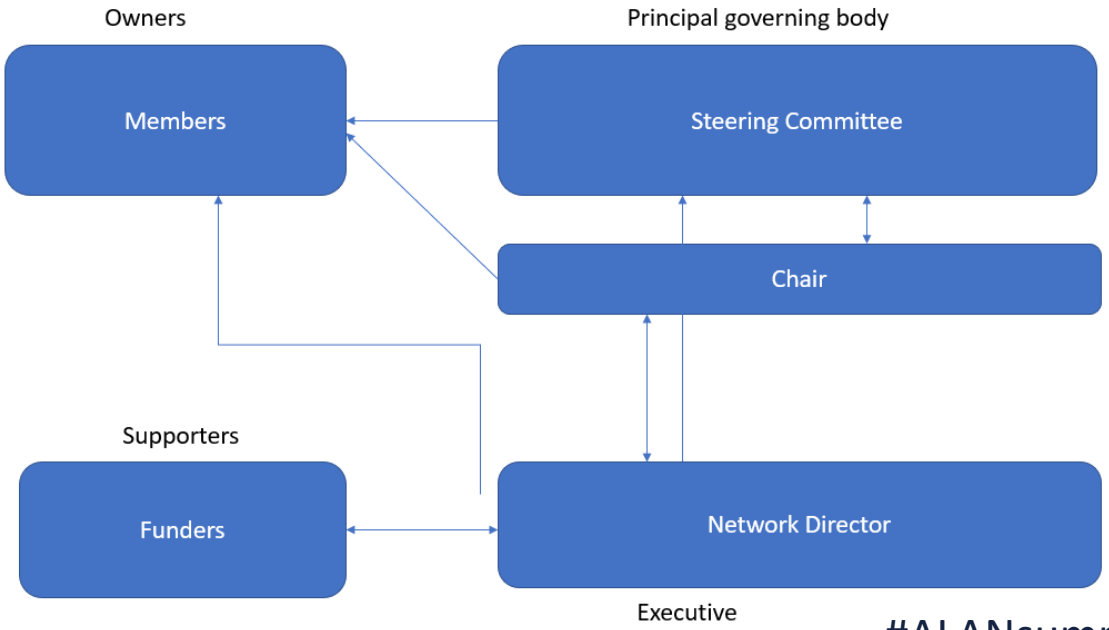
ALAN's activities are:

- Patient-led
- Collaborative
- Evidence-based

Governance

ALAN's governance model includes the following bodies, as agreed upon with the Leukemia Patient Advocates Foundation (LePAF):

- Steering Committee: Non-executive – principal governing body
- Network Director: Executive



MEET THE TEAM

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Jan Geissler
Interim Chair & Steering Committee member / LePaf representative
Email: jan@patvocates.net

Cheryl Petruk
Steering Committee member
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Elo Mapelu
Steering Committee member
Email: omapelu@gmail.com

Sophie Wintrich
Steering Committee member
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Catherine Moura
Steering Committee member
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Marine Tullet
Steering Committee member
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MEET THE TEAM

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Gereon Mänzel
Steering Committee member
Email: g.maenzel@lhrm.org

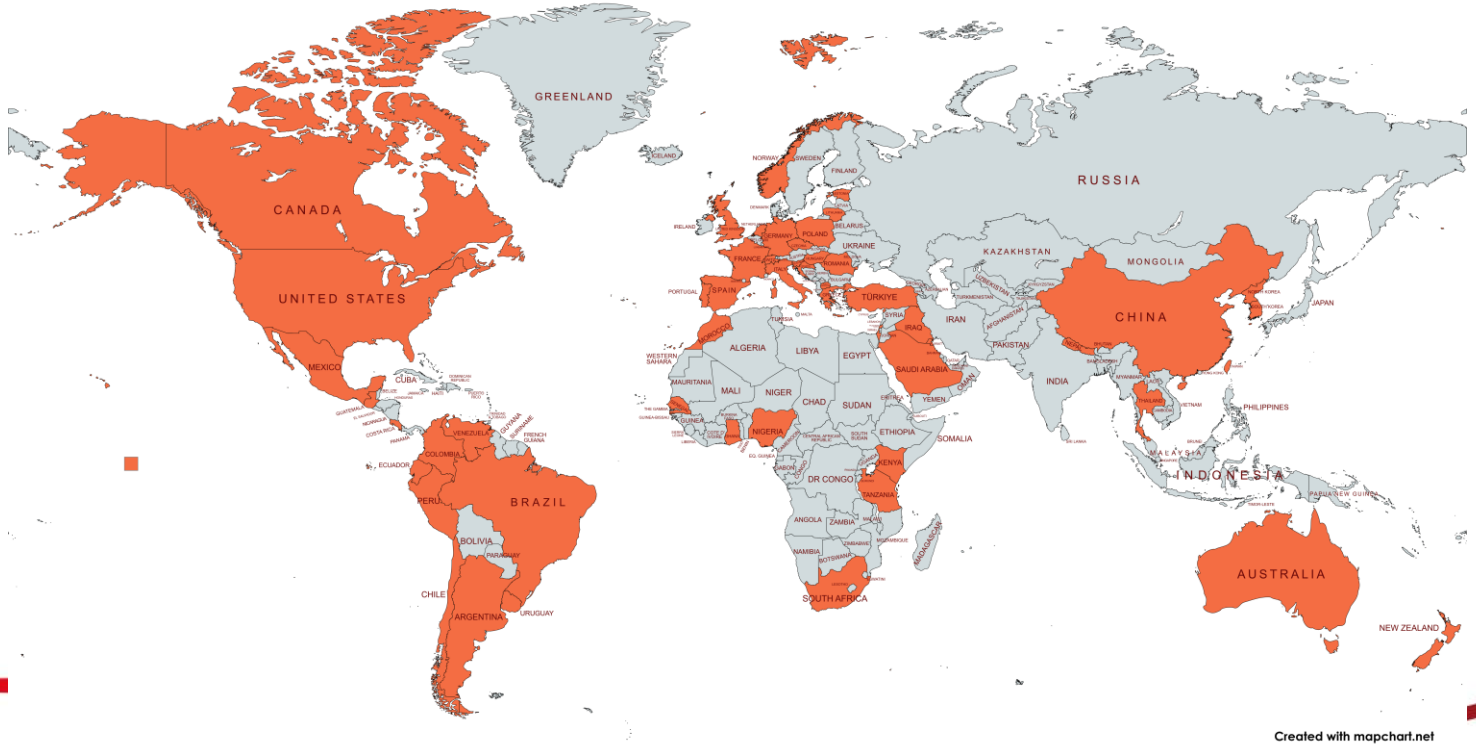
Charles McGrath
Steering Committee member
Email: charlesmcgrarth96@gmail.com

Network Management

Samantha Nier
Network Director
Email: niersamantha@outlook.com
/ samantha@acuteleuk.org

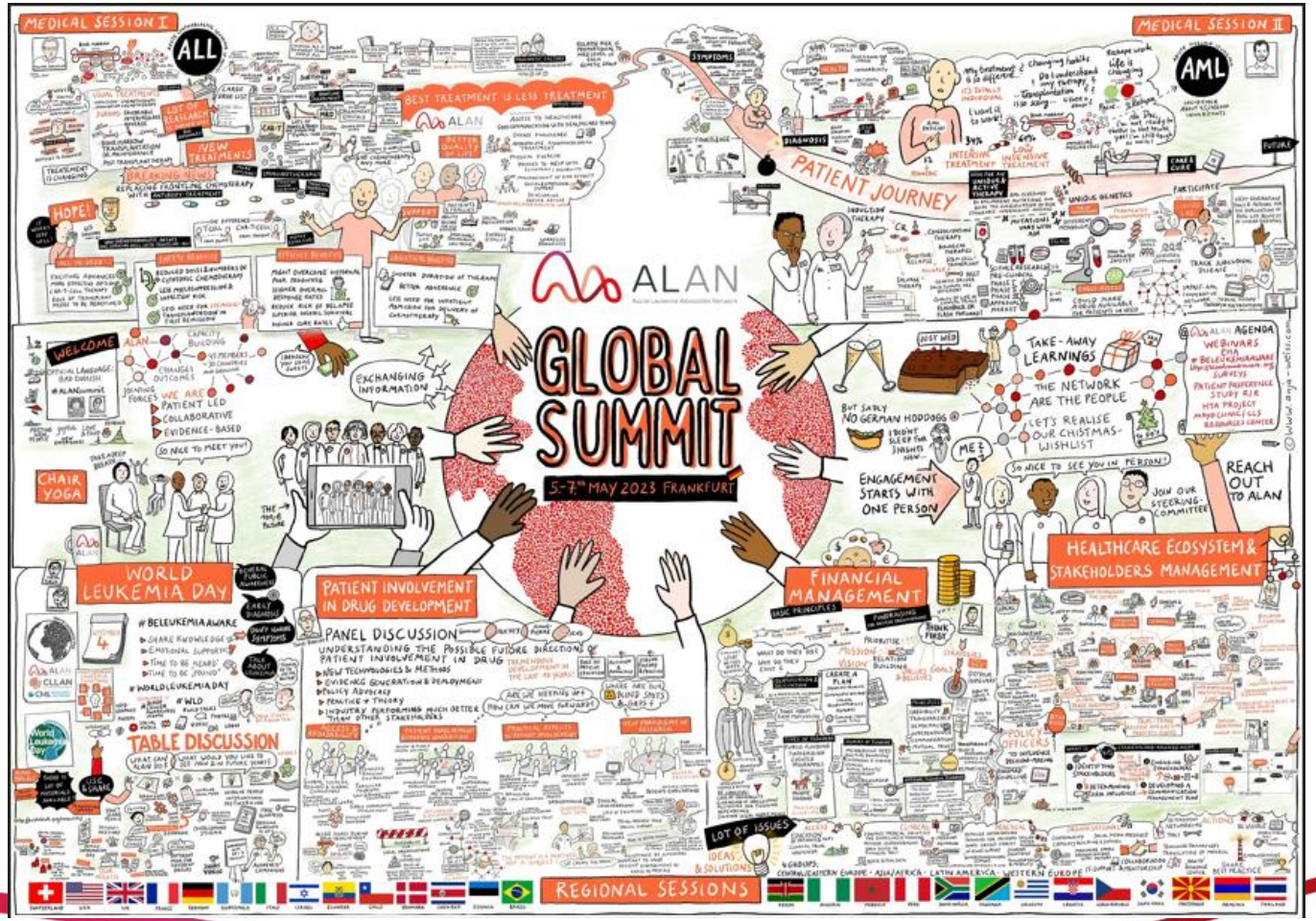
ALAN MEMBERS

Members of ALAN: 61 members in 55 countries



RETROSPECTIVE

2023



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Some numbers

Membership (organisations & countries)	61 member organisations from 55 countries.
Social Media / Audience size	Facebook: ~2,000 followers (vs ~237 in 2019) Instagram: ~907 LinkedIn: ~945 X (formerly Twitter): ~1,500
Newsletter reach	Quarterly newsletter: ~400 subscribers
Clinical trial finder usage	Over ≈12,500 users in a one-year period (Oct 2023 – Oct 2024) across all 17 cancer indications supported by Ancora.ai, including AML/ALL searches etc. Specific trials-searches: 205 for ALL, 592 for AML, from 33 countries.
Global Quality of Life Survey (Acute Leukemia)	552 respondents from 42 countries: 332 with AML, 139 with ALL, 81 with APL.
Global Leukemia Experience Survey (2021-22)	~2,629 leukemia patients responded, and 571 carers, from 79 countries.
Global Leukemia Experience Survey (2023)	~2,260 patients and 694 carers responded.
Breakdown of respondents with acute leukemia	In 2021-22 survey: of the respondents, 416 were patients with acute leukemia, and 210 carers of acute leukemia patients. In 2023 survey: of the respondents, 641 were patients with acute leukemia and 392 carers of acute leukemia patients.

Major projects and Outcomes

Major Activities & Projects	Highlights / Outputs
• **Evidence based advocacy:** continued large-scale surveys: Global Quality of Life Survey, Leukemia Patients and Carers Experience Survey, Patient Preference Study • **Awareness campaign:** continued promotion of public understanding **#BeLeukemiaAware, BCAM, #WeAreMen** • **Started / continued involvement with external research / policy initiatives** • **Growing community engagement** – more communication, better tools, more support to member groups. • **Providing a Resources Center** – developing more tools, information materials, guidance • **Continuous online education** (webinars, seminars, congress report, ALAN Summit)	• Publication of reports, posters and **5** journal articles • More internal tools for advocates (e.g. toolkits, best practice sharing). • More input into policy and research discussions, particularly via evidence from patient/carer surveys. • Raised visibility of acute leukemia issues among policy/research stakeholders • Strengthened governance, business continuity, operating rules etc. to support sustainability. • Strengthened engagement at congresses; more materials for advocates • More robust resources for patients/carers

What do we do well?

- **Acute disease focus**: Acute leukemias have different challenges (fast onset, urgent treatment), so ALAN's tailored surveys and work in this area are especially valuable, filling a gap compared to networks focused on chronic leukemias.

- **Investment in evidence**: ALAN is producing peer-reviewed published data, QoL metrics, etc., which gives strong base for advocacy.
  - 5 journal articles in 3 years (we are the only ones in hem-onc)

- **Combined collaboration with other networks**: Many surveys are done in collaboration (ALAN + CLLAN + CMLAN), which helps share reach & resources, cross-comparisons, etc.

- **Rapid engagement and tool development**: The progression from first surveys to toolkits, resource center, awareness campaigns shows not just data gathering but translating into resource outputs

What could we do better?

- **Closing the gap between awareness & access**: While awareness and advocacy are growing, ensuring concrete improvements in access to care, diagnostics, treatment (especially in lower/middle income countries) remains a big challenge.

- **Implementation of findings**: Surveys and preference studies generate a lot of data; turning that into policy change, guideline changes, or improved care at local/national levels may require more resources and support.

- **Sustainability and funding**: As with many networks, reliance on external sponsors, the need for robust governance, and continuity of operations are critical. ALAN has taken steps (governance, business continuity plans) but this is an ongoing requirement.

- **Engagement in diverse regions**: Ensuring that the voice of patient groups from all world regions, including low- and middle-income settings, is heard, represented, and supported.

- **Measurable impact metrics**: While we report a lot of activity from our evidence-based advocacy work, there is less data or outcome metrics (e.g. changes in patient survival, treatment delays, policy change) available. It may take more time or more formal evaluation to show this.

Long story short

Over the past three years, ALAN has:

- Consolidated its role and matured as a global network for acute leukemia advocacy
- Built a stronger foundation in gathering patient/carer evidence and using it to inform advocacy
- Expanded capacity, both among member organisations and through tools & resources
- Raised visibility for acute leukemia issues — among patients, carers, healthcare providers, and policy stakeholders
- Strengthened collaborations and external partnerships.

Note: The progress is quite substantial given the complexity of health systems, regulatory environments, and the disparity in resources globally.

ALAN appears well-positioned to increasingly influence policy, improve access to treatment, and improve quality of life for patients — but the next frontier will likely be moving from awareness and evidence towards concrete policy/health-service change and ensuring sustainable impact in diverse settings.

2017

2025

- Thought leaders
- Pioneers
- Community leaders across hematology
- Collaborators
- Capacity building and member support

Now,
It's
Your
Turn

What are you most proud of in your advocacy "career"?

LINK
https://www.menti.com/alt8mjx2x3cs

Or SCAN THE QR CODE

Click to download as image

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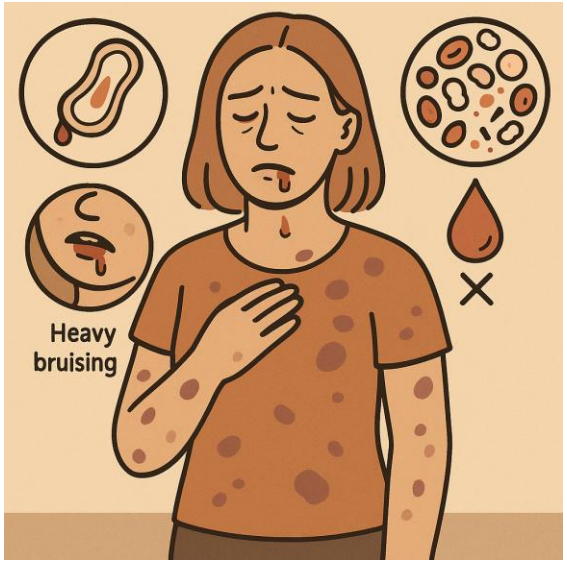
MEDICAL SESSION

Charles McGrath, Carolina Garcez, Giovanni Marconi

Patient 1

Mary, a **48-year-old** woman, has felt very weak for 3 days, with **easy bruising, heavy menstrual bleeding and bleeding gums**. On exam, she looks **pale**, has **multiple bruises**, and mild gum bleeding.

Lab tests show very **low red and white blood cells and platelets**. Her blood is not clotting normally, and she has signs of a dangerous **body-wide bleeding and clotting problem**.



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As a patient advocate, what is the most important next step to push for?

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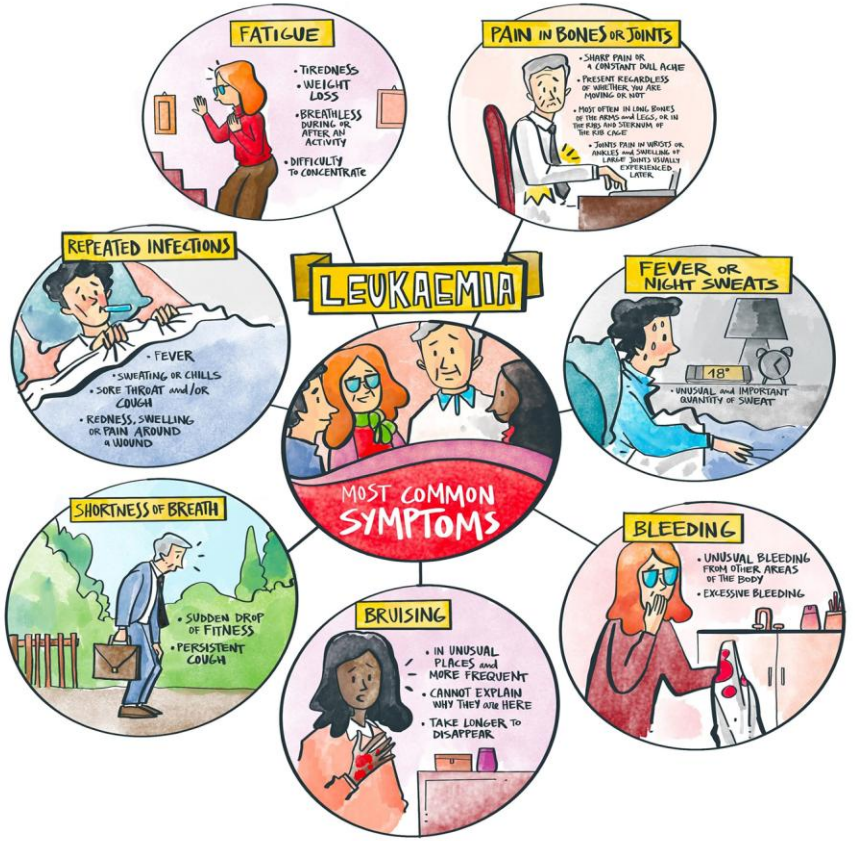
UNDERSTANDING THE DIAGNOSIS

Symptoms

https://acuteleuk.org/downloads/infographics/?2746



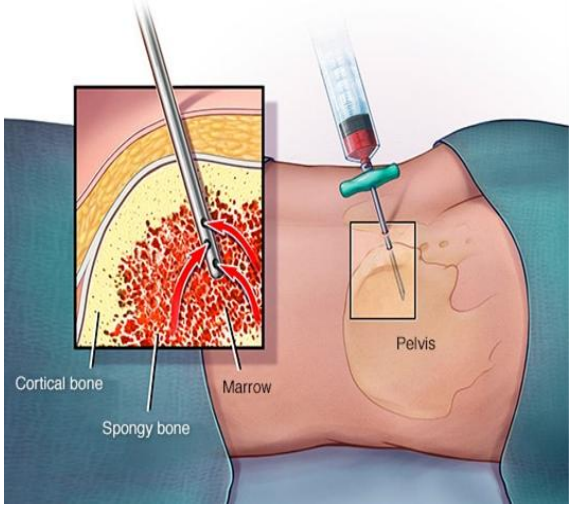
General approach at Diagnosis

A patient who might have acute leukemia needs:

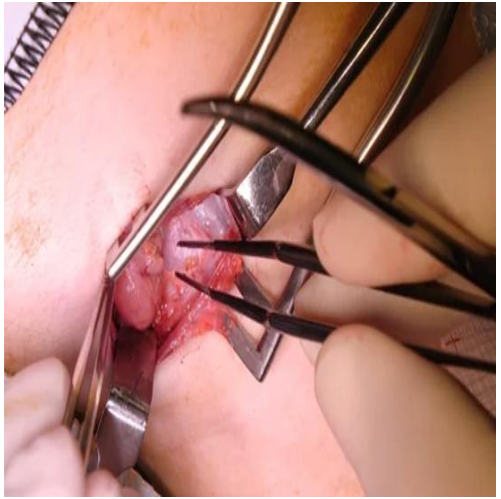
- A full clinical evaluation
- Blood tests
- Looking at the blood and bone marrow under the microscope
- Special tests on the leukemia cells to understand exactly what type it is

These steps guide treatment.

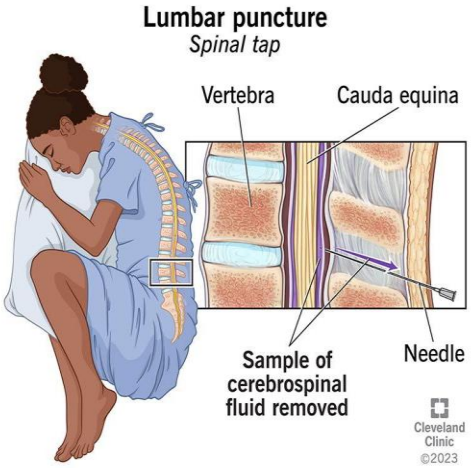
Diagnostic Procedures



Bone marrow biopsy
Bone marrow aspirate

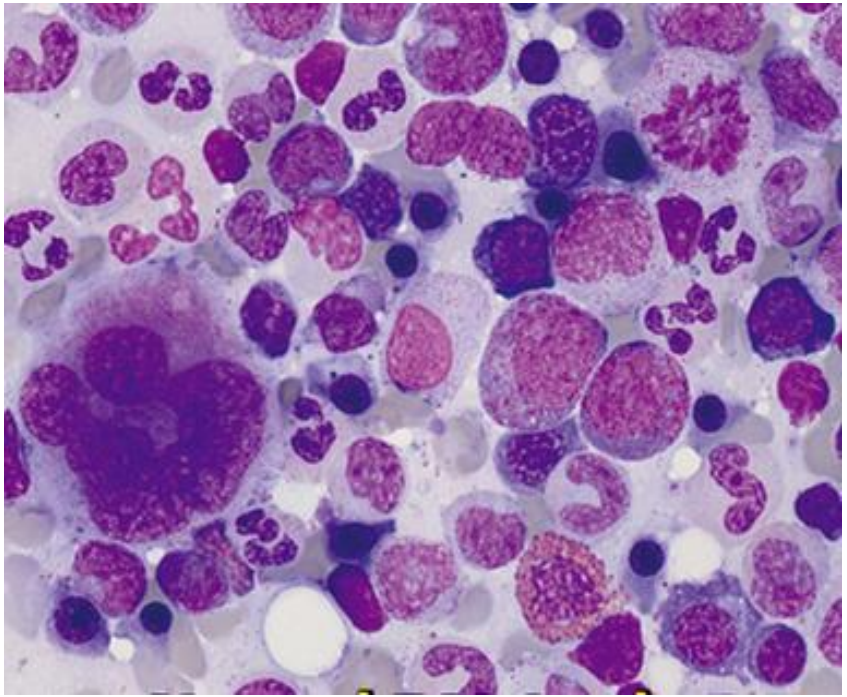


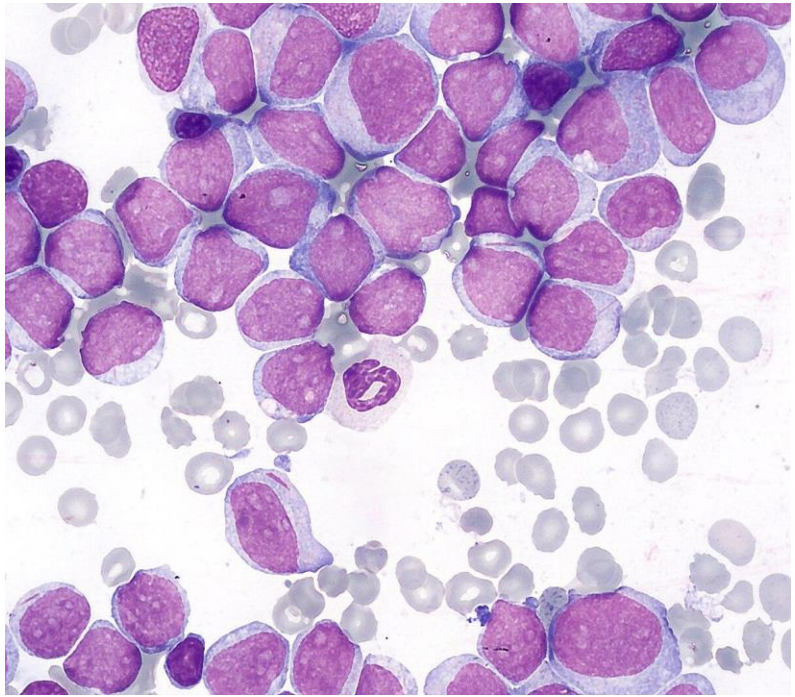
Lymph node biopsy



Lumbar Puncture

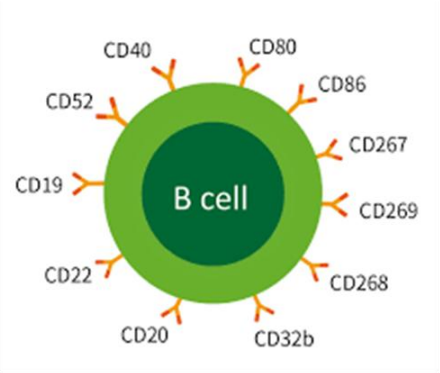
Cytological diagnosis

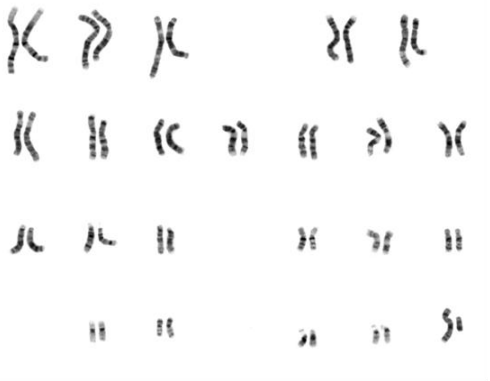


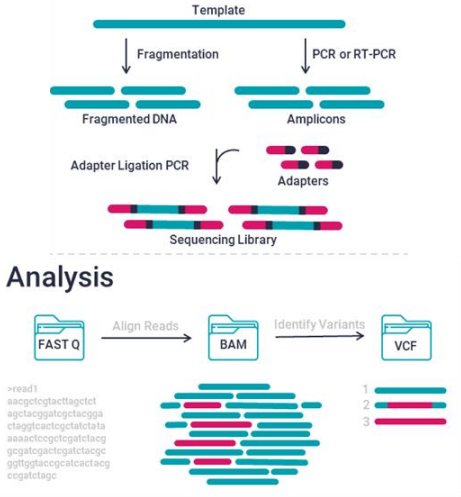


Cytological diagnosis

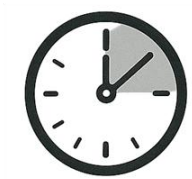
Tests on the samples







Flow cytometry



2 DAYS

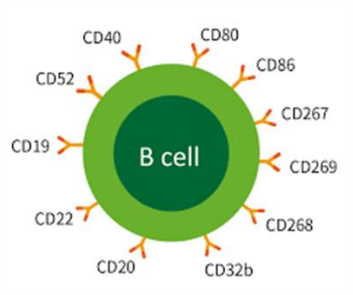
Karyotype

7 DAYS

NGS

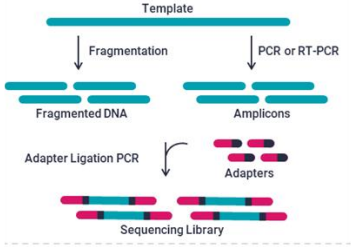
14 DAYS

Tests on the samples

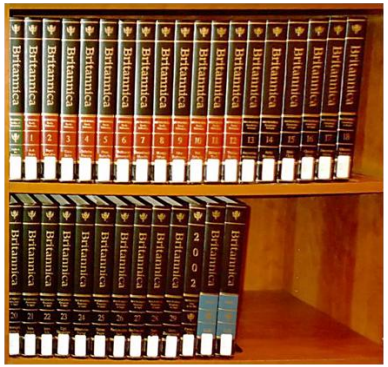


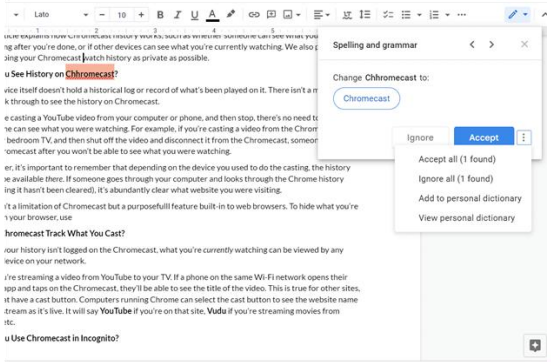
Flow cytometry

Karyotype



NGS





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What role can patient advocates play in helping others navigate this phase?

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What is the main need to diagnose leukemia quickly and accurately in your country

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Patient 1 continuation

After receiving her initial diagnosis of acute leukemia, Mary was promptly started on ATRA (on the suspicion of APL) and emergency supportive measures to address a severe clinical presentation, including a high risk of life-threatening bleeding. This urgent intervention helped stabilize her condition, even though not all test results were back yet.

Now that she is clinically stable, her doctors explain that they still need to wait for the results of specific molecular and genetic tests before deciding on the next phase of her leukemia treatment. Mary feels confused… if this is such an urgent disease, why wait now?

Do not edit
How to change the design

As a patient advocate, how would you explain the main reason her doctors are performing these genetic tests at this stage?

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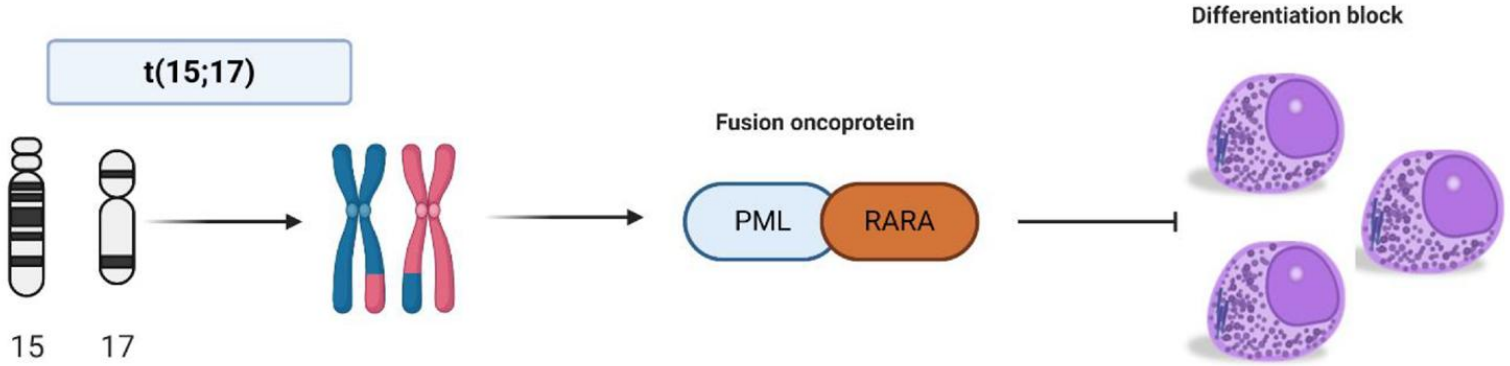
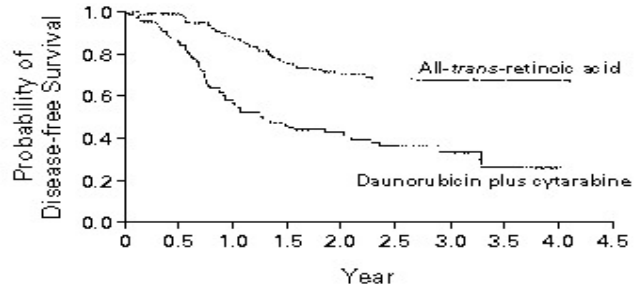
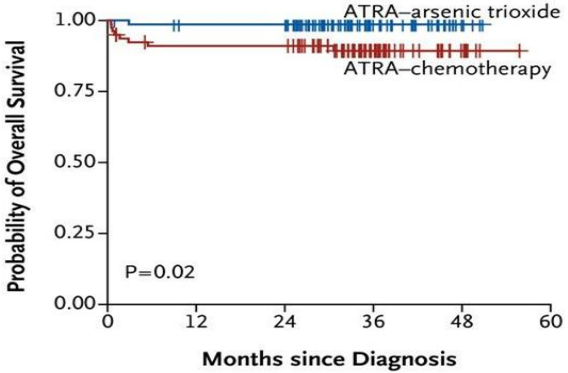
GENETIC AND MOLECULAR TESTING: GUIDING TREATMENT DECISIONS





	1ST YR	2ND YR	3RD YR	4TH YR	5TH YR
	no. of events/no. at risk				
Daunorubicin plus cytarabine	49/120	14/61	6/35	1/8	0/0
All-*trans*-retinoic acid	15/124	18/98	2/67	0/21	1/3

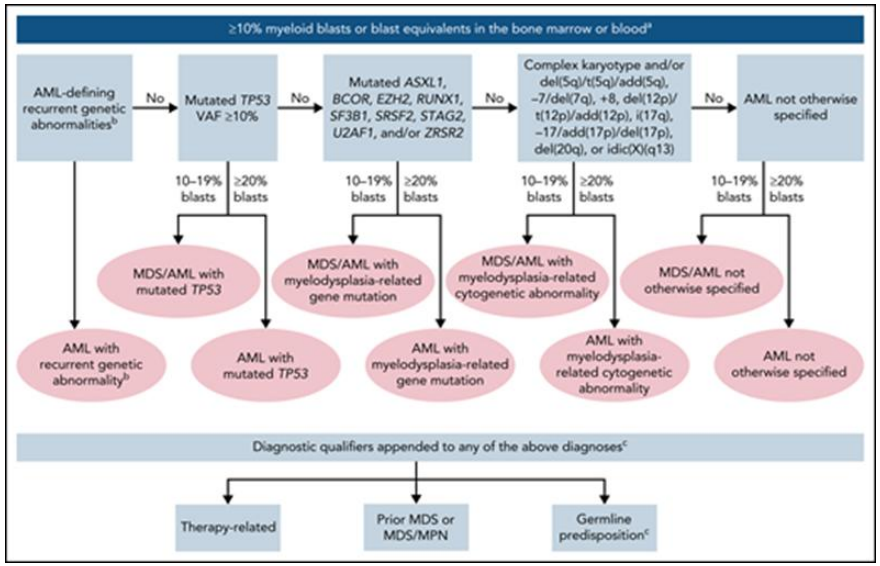
Tallman, NEJM, 1997



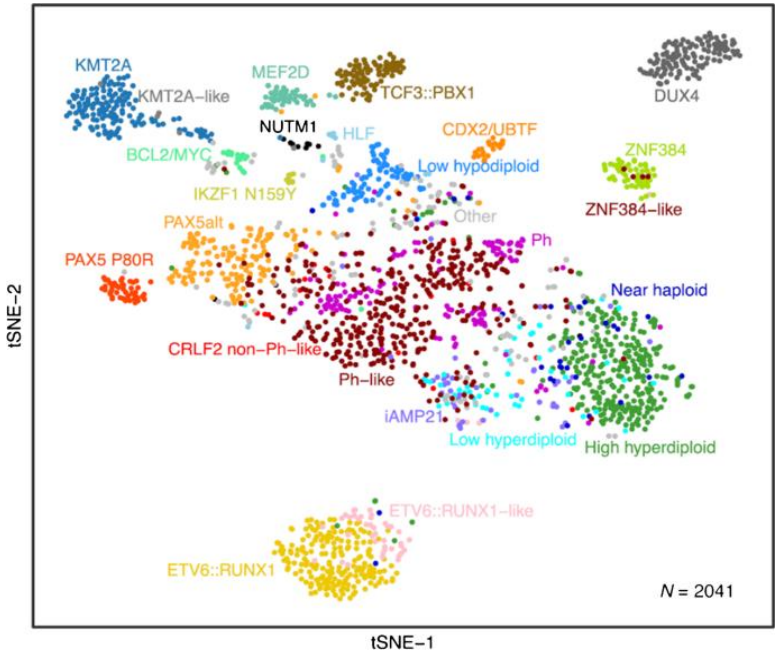
No. at Risk					
ATRA–arsenic trioxide	77	73	73	29	5
ATRA–chemotherapy	79	69	69	29	7

LoCoco NEJM 2013

A classification and treatment paradigm based on genetic

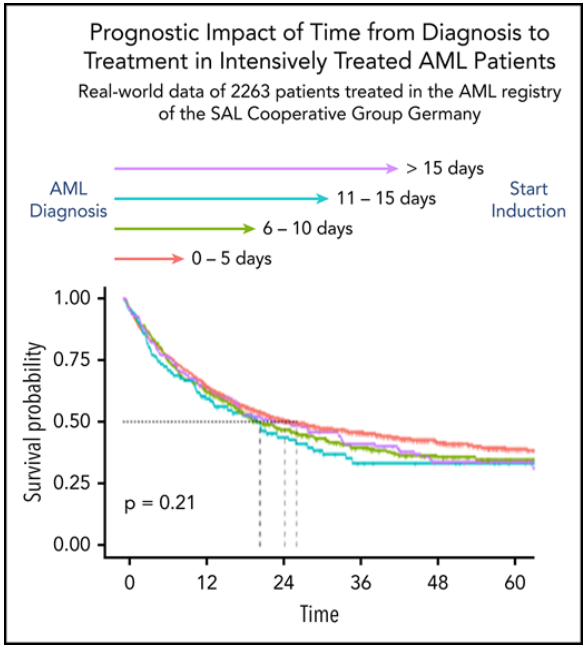


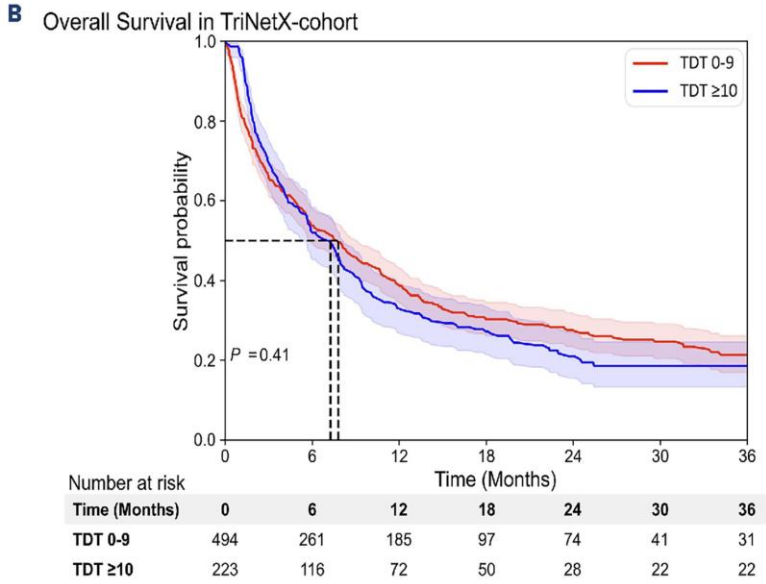
Arber, Leukemia, 2022



Nature, 2022

How much time is typically acceptable between confirming a diagnosis of acute leukemia and starting treatment, especially when waiting for molecular or cytogenetic results?





Bertoli Blood 2013, Rollig 2020, Baden 2024

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What can be done to shorten the diagnostic timeline or at least make the waiting period feel less disempowering?

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Patient 1 continuation

After her treatment, **Mary** hears her doctor mention that her leukemia could be *“**de novo**”* or *“**secondary**.”*
These words sound unfamiliar and a bit worrying.

Later, her care team also mentions **germline testing** and Mary begins to wonder what that means and whether it might affect her children.

Mary asks:

> “Does this mean my leukemia could be something I was born with or something I could pass on to my kids?”

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As a patient advocate, what might be the main reason Mary's doctors are suggesting germline testing?

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GERMLINE TESTING & FAMILIAL RISK

THE WORDS 'DE NOVO OR SECONDARY' MAY BE MENTIONED TO YOU AT POINT OF DIAGNOSIS. LIKE MANY OF THE NEW WORDS, THESE CAN SEEM SCARY, LET US EXPLAIN THEM FOR YOU...

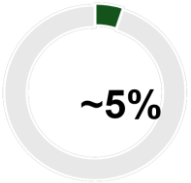
DE NOVO

MEANS YOU HAVE NOT HAD ANY PREVIOUS CLINICAL HISTORY RELATING TO MYELODYSPLASTIC SYNDROME (MDS), MYELOPROLIFERATIVE DISORDER OR HAD ANY EXPOSURE TO POTENTIALLY LEUKEMOGENIC (POTENTIAL CAUSES OF LEUKEMIA) THERAPIES.

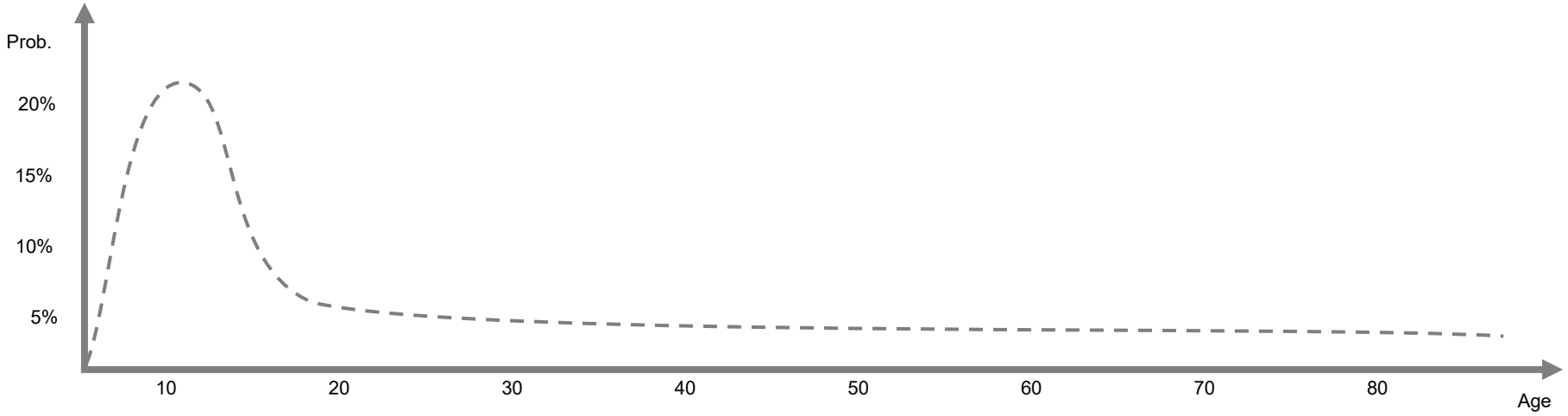
SECONDARY

THIS IS WHEN THE LEUKEMIA HAS EVOLVED FROM A PREVIOUS MYELODYSPLASIA, MYELOPROLIFERATIVE DISORDER OR APLASTIC ANAEMIA OR POTENTIAL EXPOSURE TO LEUKEMOGENIC THERAPIES - WITH OR WITHOUT TREATMENT.

Germline predisposition

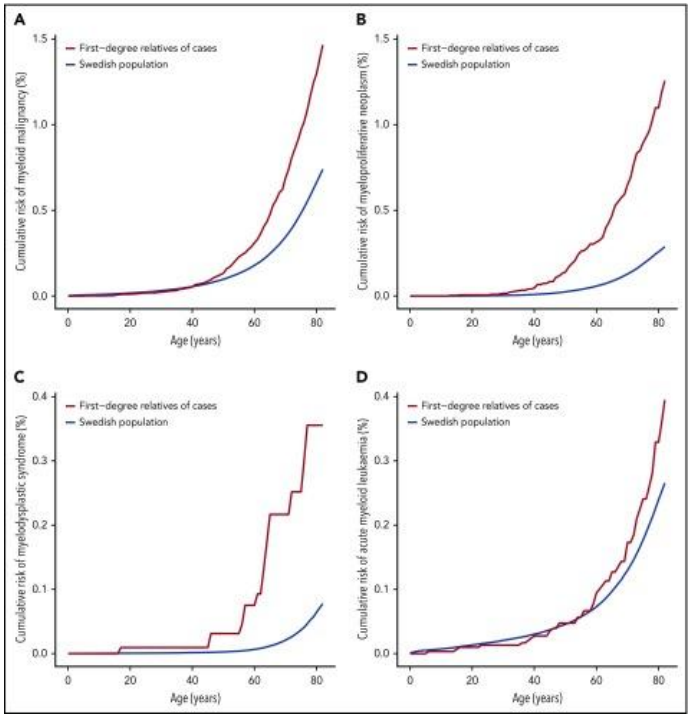


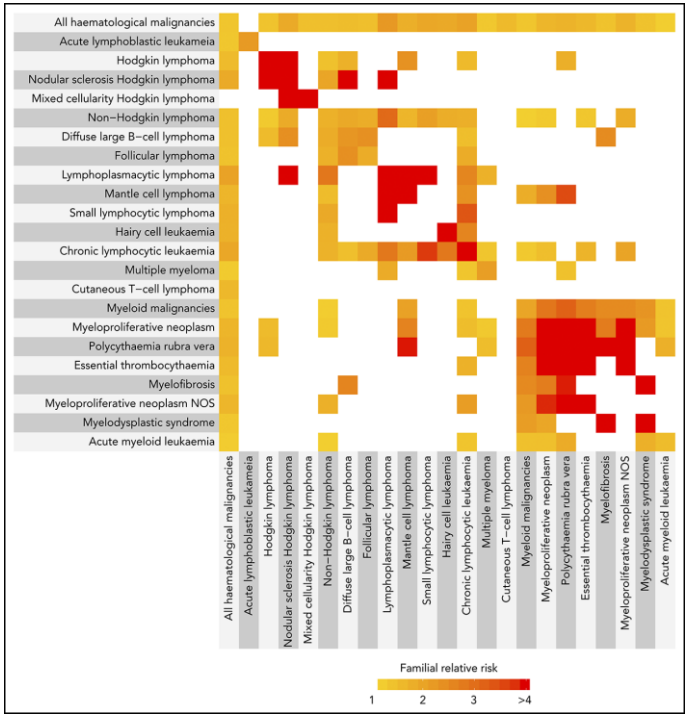
Acute leukemia has germline predisposition



Reinig, leukemia 2023, adapted

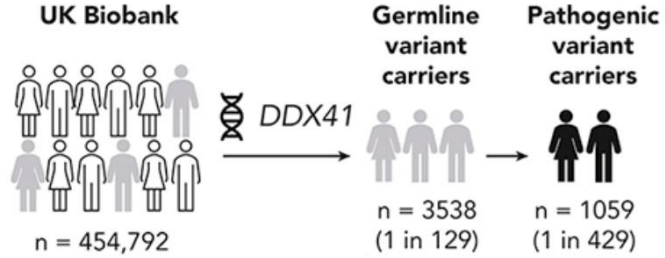
Familiar risk is different





Sud, blood 2018, Sud Blood 2019

New germline predispositions, an example

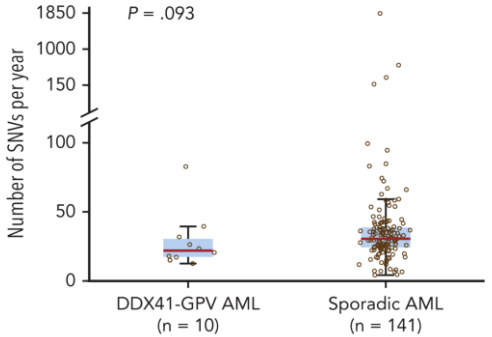


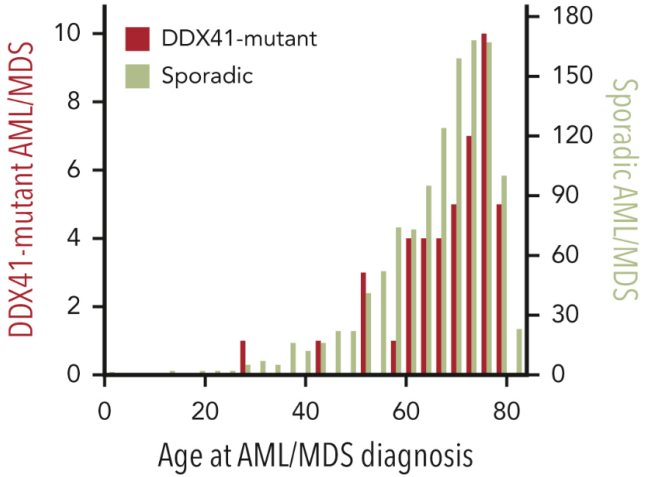
Odds ratios for AML/MDS

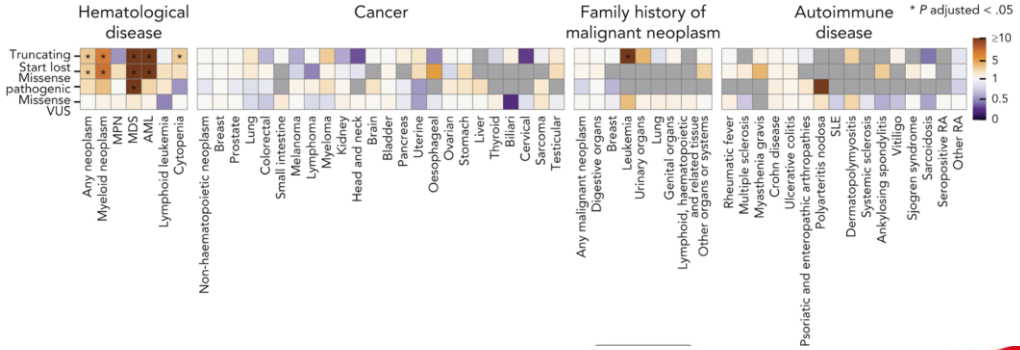
DDX41 truncating: 15.1

DDX41 missense: 7.5

DDX41 start-lost:12.9







Sruthi Cheloor Kovilakam, Blood, 2023

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What role can patient advocates play in ensuring that germline testing leads to understanding, not anxiety, within families?

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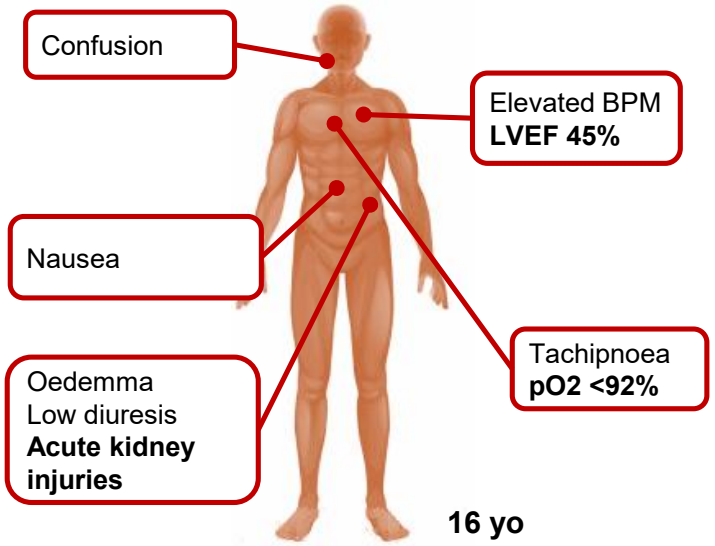
Patient 2

John, a **16-year-old** boy, comes to the ER after a week of **worsening fatigue and shortness of breath.**

His parents noticed unusual **bruises** on his legs and arms, and in the past two days, he has become **confused and nauseated**.

On examination, he looks very **pale and weak**. His heart rate is fast, he is breathing quickly, and his **oxygen levels are below normal.** His legs are **swollen**, and he has very little urine output.

Based on labs results, the medical team suspects that his body is struggling with **serious complications involving the heart, lungs, and kidneys.**



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What factor will most influence the doctors' decision on how aggressive his leukemia treatment can safely be?

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TAILORING TREATMENT: DECISION TREES BASED ON PATIENT FITNESS

How to define treatment intensity?

GO

- Completelly independent for daily living activities
- No major organ damage
- Long life expectancy without the disease

SLOW-GO

Old (>75 yo) or
At least one significant comorbidity

NO-GO

Severe comorbidity with severe disability

How to define treatment intensity?

GO

High dose treatment

- Completelly independent for daily living activities
- No major organ damage
- Long life expectancy without the disease

SLOW-GO

Reduced intensity treatment

Old (>75 yo) or
At least one significant comorbidity

NO-GO

Supportive care only

Severe comorbidity
with severe disability

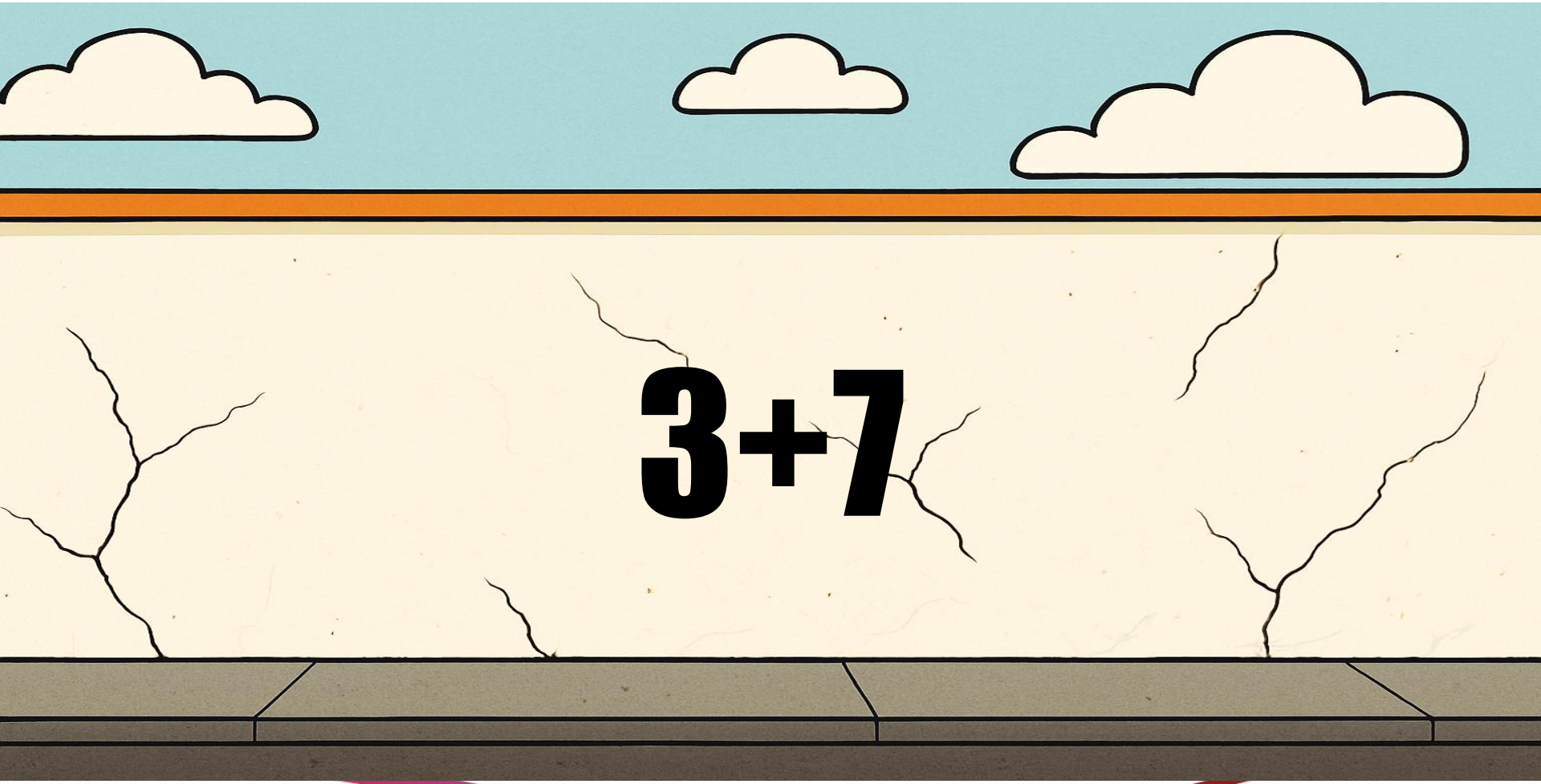
FIRST-LINE THERAPIES: STANDARD OF CARE TREATMENTS TODAY

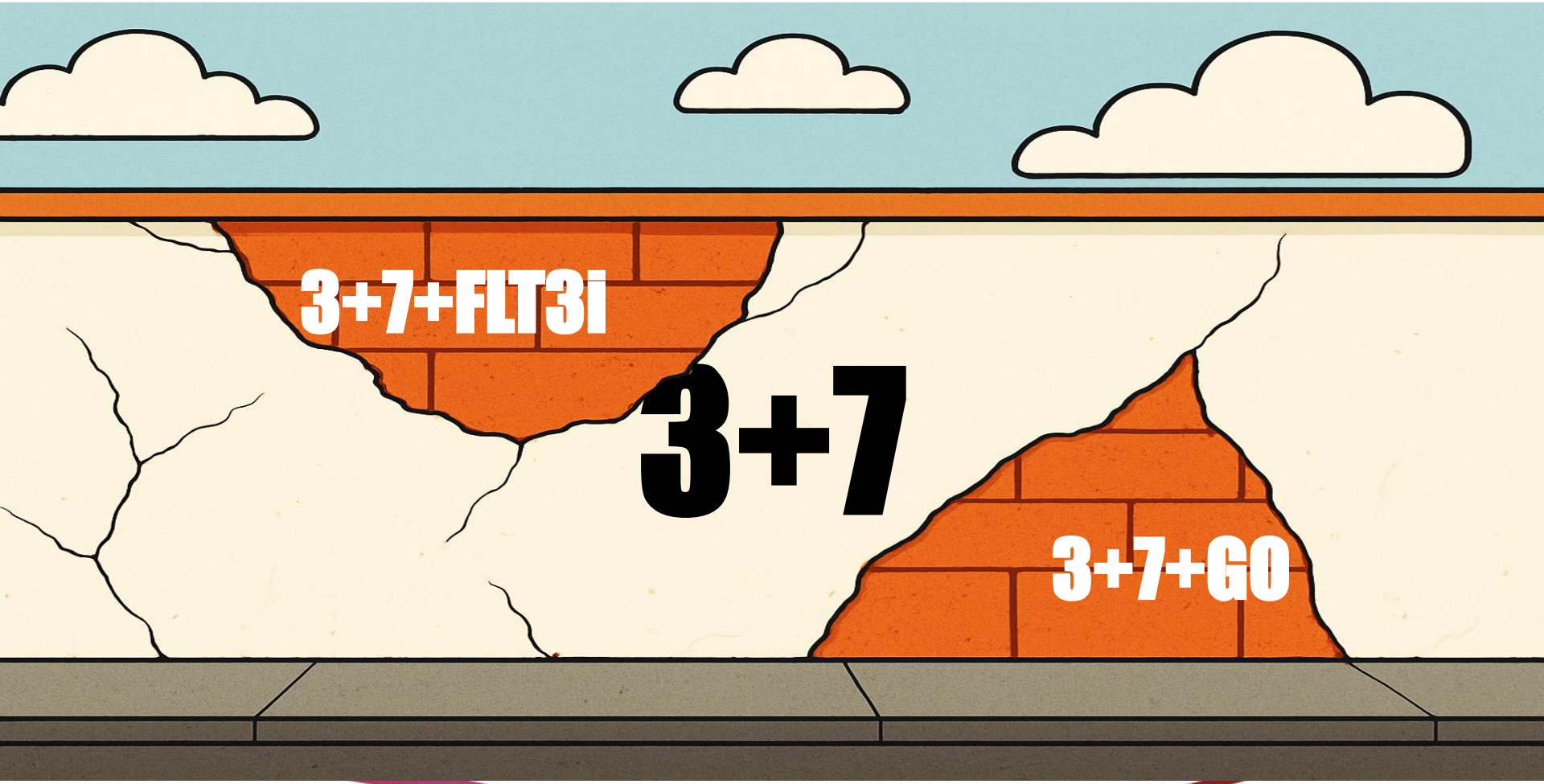
1 INDUCTION THERAPY

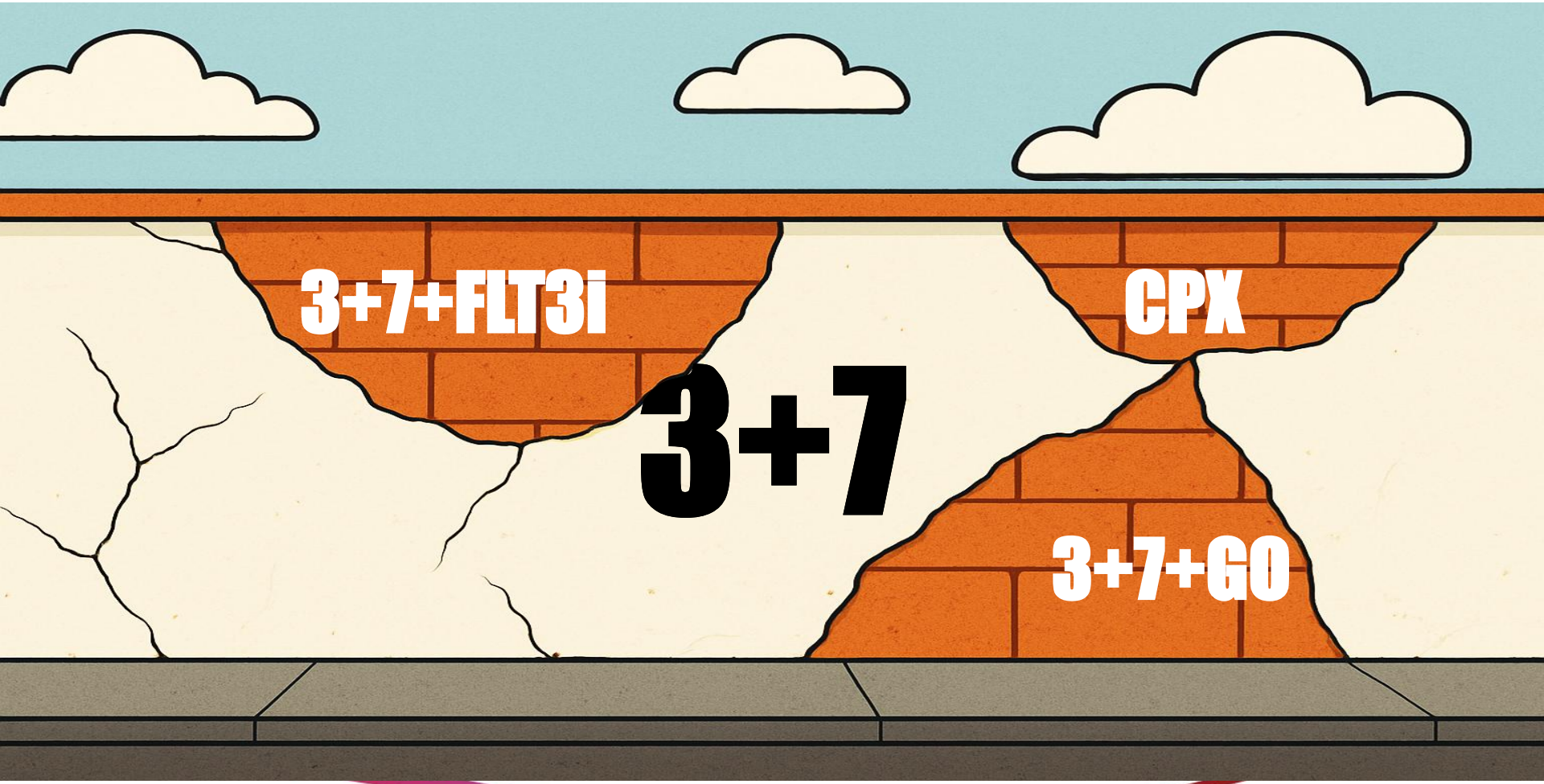
- AIMED AT QUICKLY GETTING RID OF AS MANY LEUKEMIA CELLS AS POSSIBLE
- INTENSITY OF TREATMENT DEPENDS ON PATIENT'S AGE AND HEALTH
- DOCTORS OFTEN GIVE THE MOST INTENSIVE THERAPY TO PATIENTS YOUNGER THAN 60 YEARS, BUT SOME OLDER FIT PATIENTS MAY BENEFIT FROM SIMILAR OR SLIGHTLY LESS INTENSIVE TREATMENT

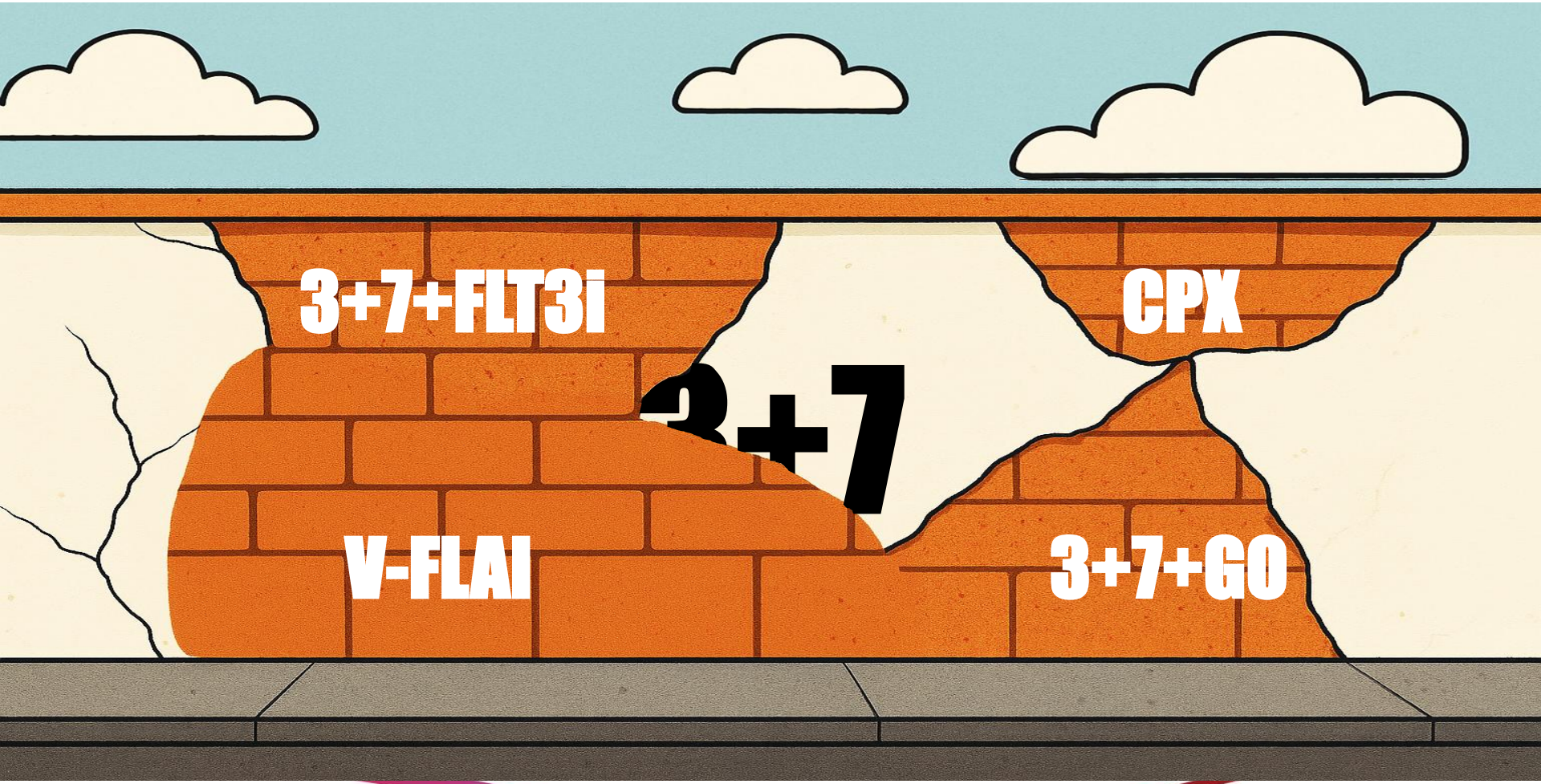
2 CONSOLIDATION

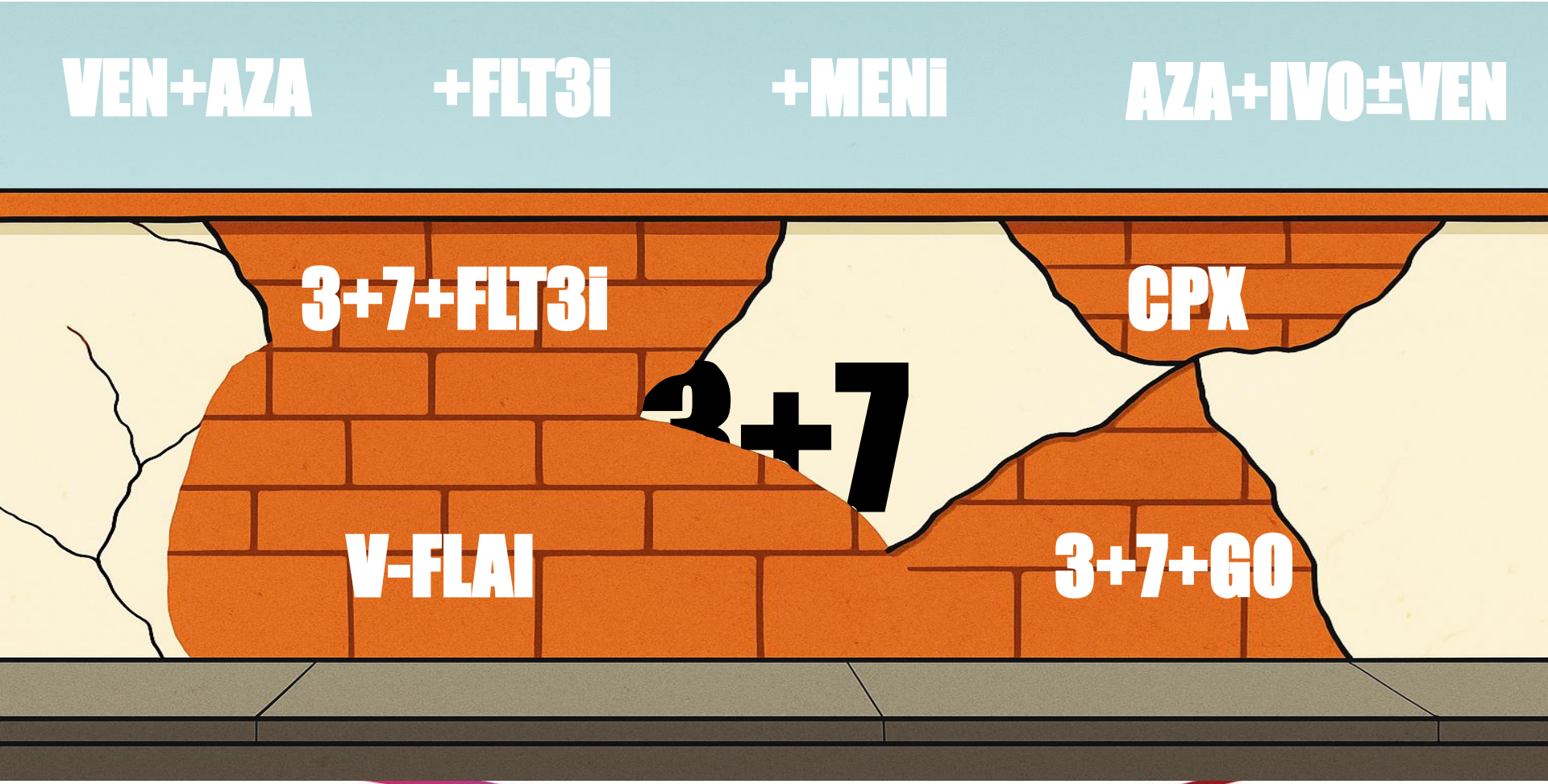
THE AIM IS TO CLEAN UP ANY 'LEFT OVER' LEUKEMIA CELLS. YOU WILL LIKELY HAVE 1 OR MORE ROUND BEFORE YOUR DOCTOR MAY THEN CONSIDER YOUR CHEMOTHERAPY BEING STOPPED.

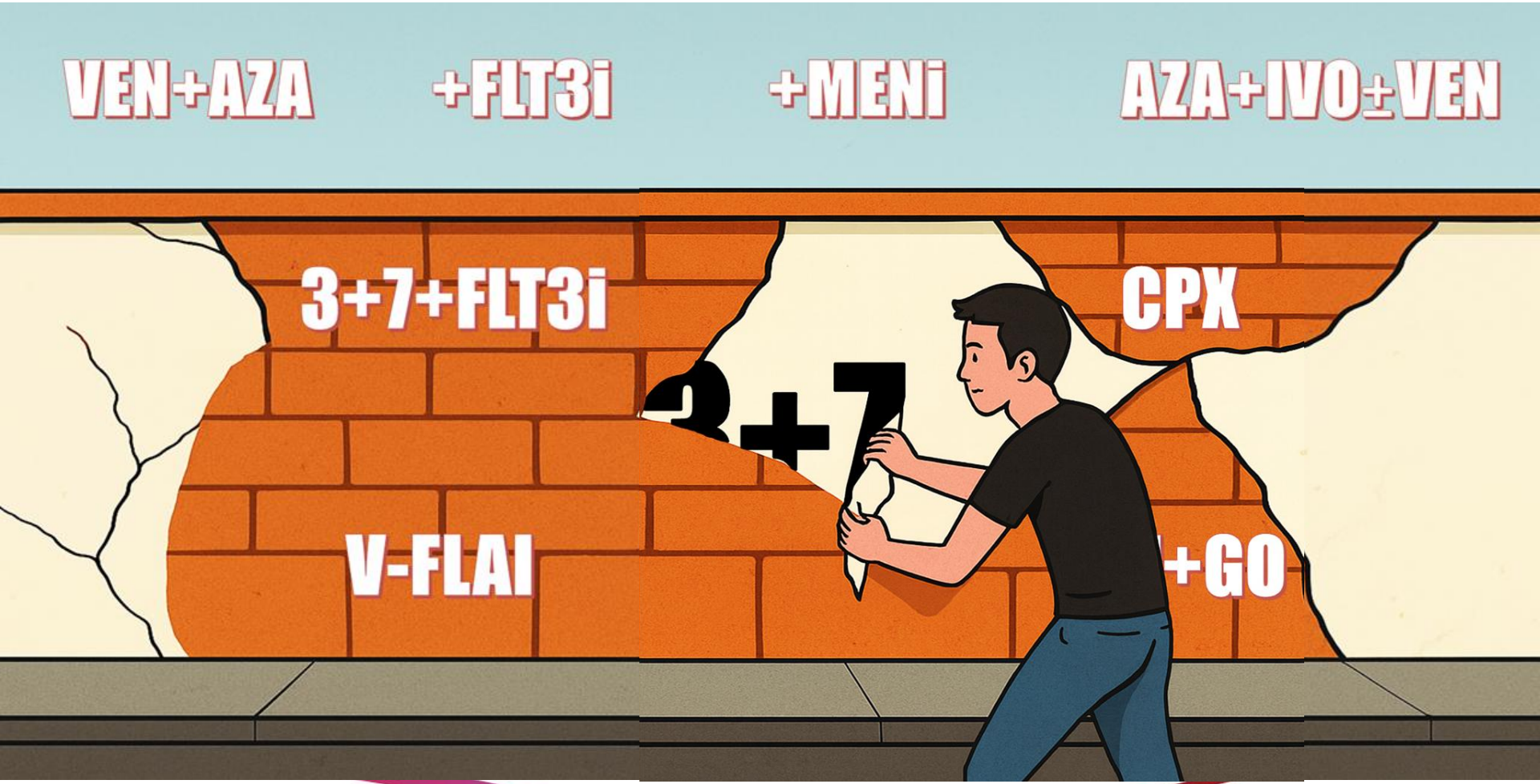

3+7


3+7+FLT3i
3+7
3+7+GO

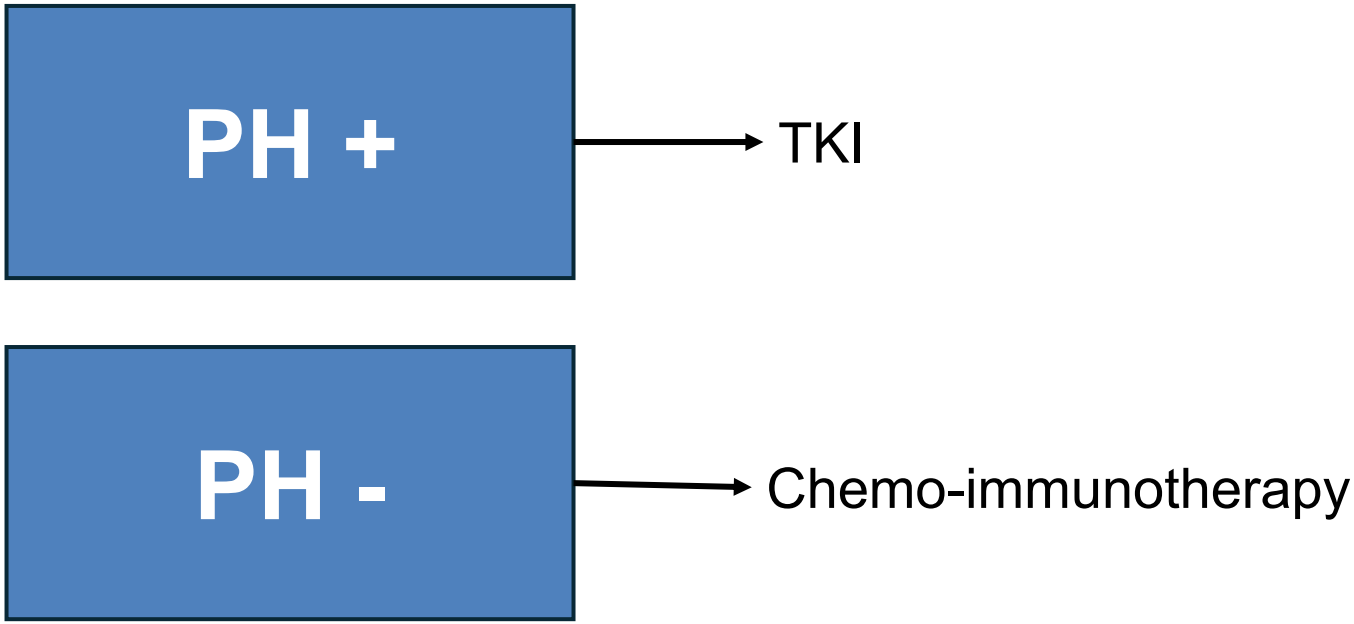

3+7+FLT3i
CPX
3+7
3+7+GO

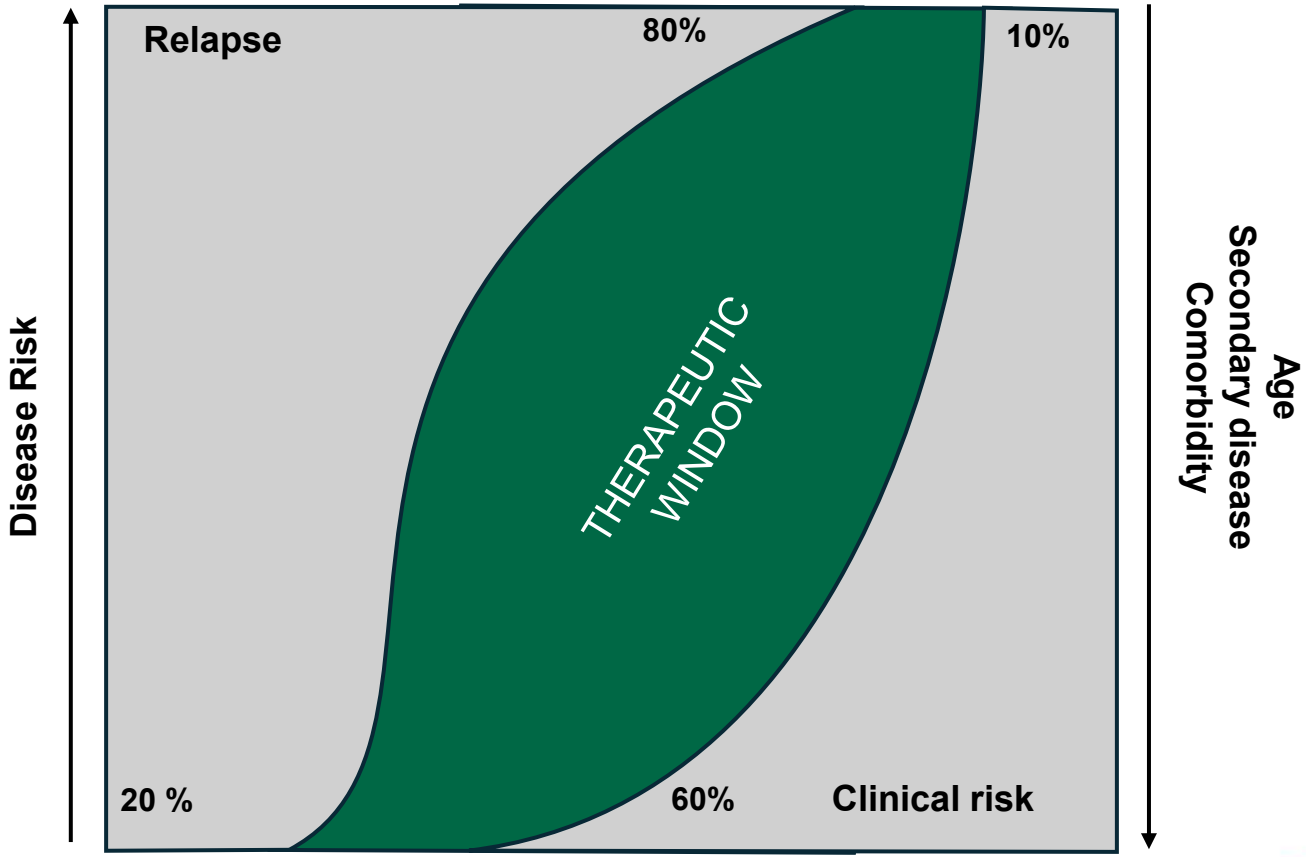

3+7+FLT3i
CPX
3+7
V-FLAI
3+7+GO


VEN+AZA
+FLT3i
+MENi
AZA+IVO±VEN
3+7+FLT3i
CPX
3+7
V-FLAI
3+7+GO

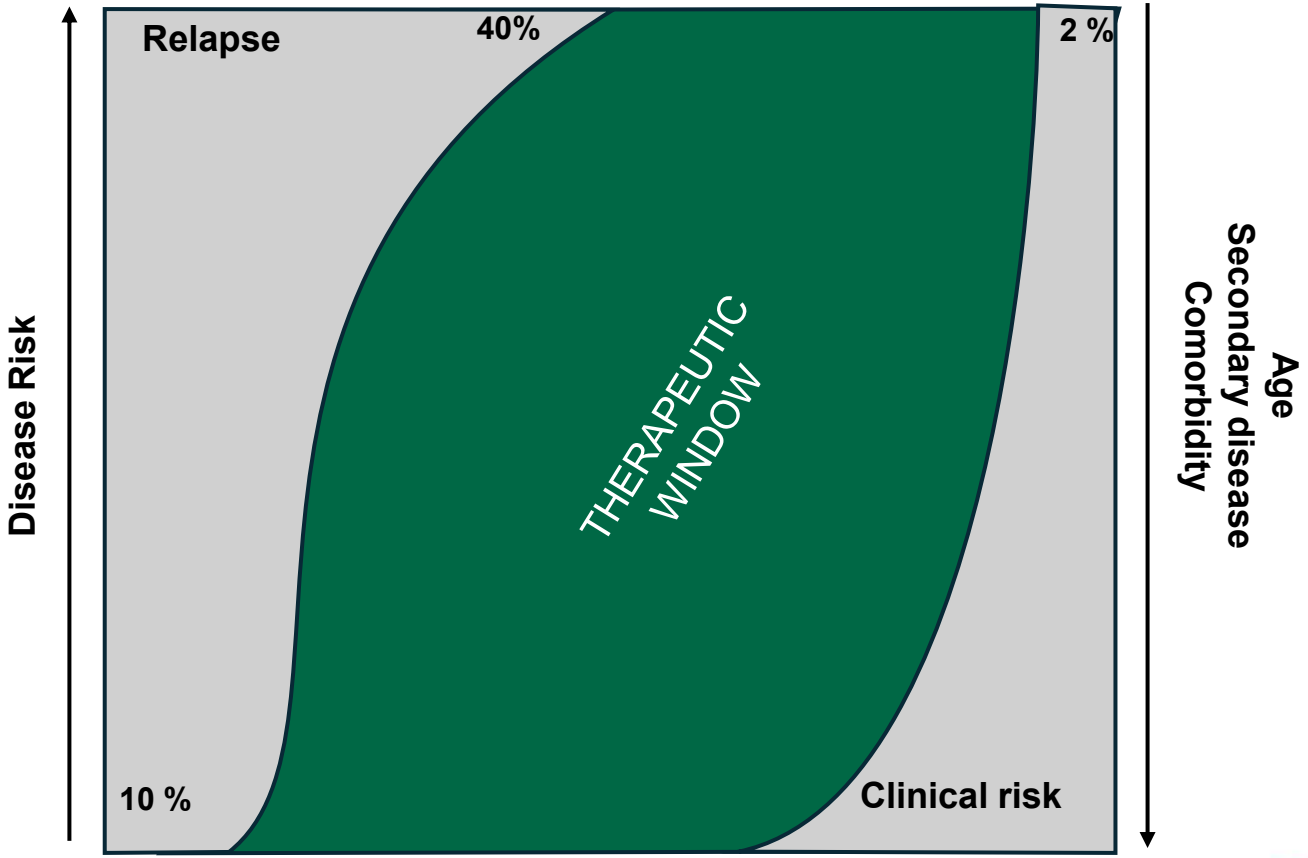

VEN+AZA
+FLT3i
+MENi
AZA+IVO±VEN
3+7+FLT3i
CPX
3+7
V-FLAI
+GO

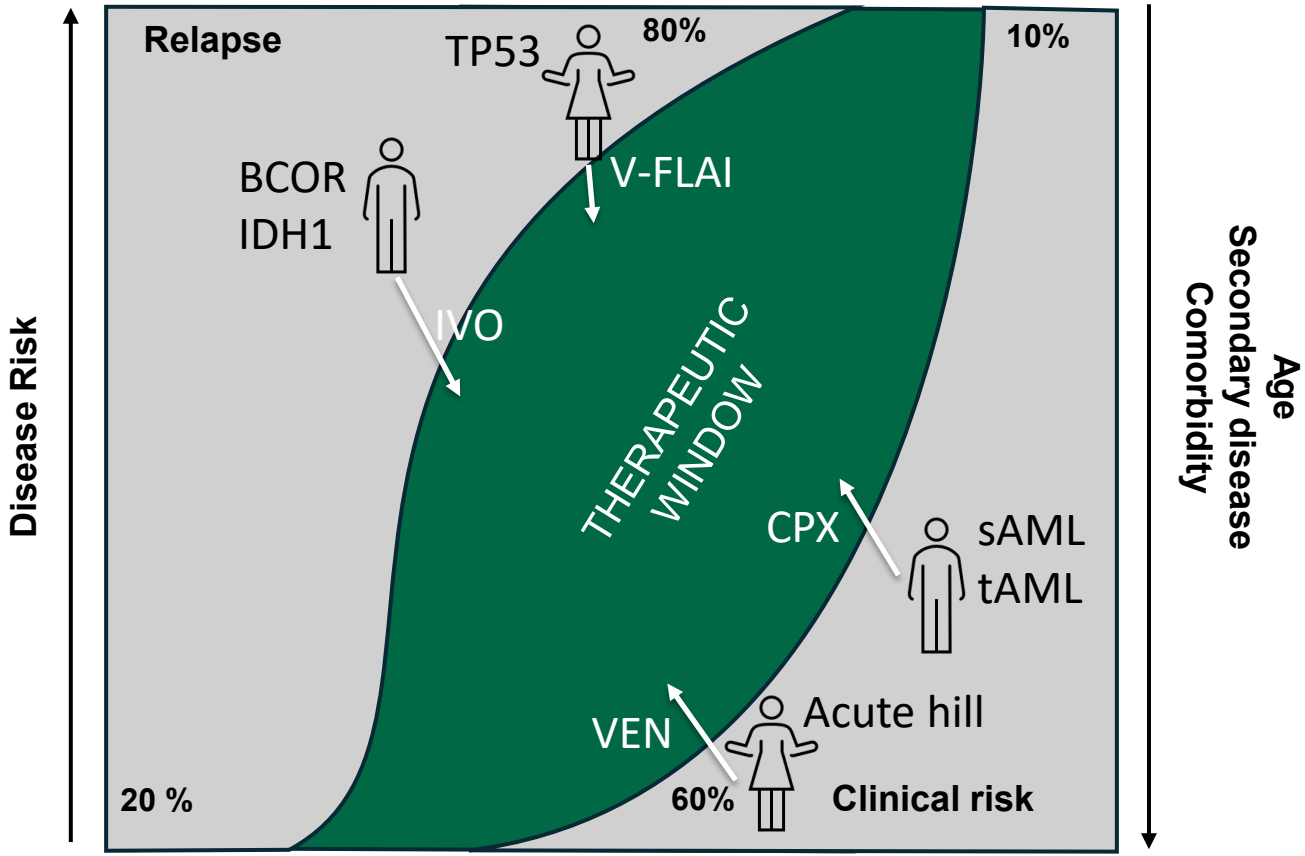
Ph+ ALL as an example




Relapse
80%
10%
THERAPEUTIC WINDOW
Disease Risk
Age
Secondary disease
Comorbidity
20 %
60%
Clinical risk

Pona-blina
Vs
Ima-CHT




Relapse
TP53
80%
10%
BCOR
IDH1
V-FLAI
IVO
THERAPEUTIC WINDOW
CPX
sAML
tAML
VEN
Acute hill
20 %
60%
Clinical risk
Disease Risk
Age
Secondary disease
Comorbidity

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Audience Q&A

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Access to Leukemia Treatment Options in Low- and Middle-Income Countries

Barriers

- Restricted availability of chemotherapeutic agents,
- Inadequate supportive care (antimicrobials, blood products),
- and high rates of treatment abandonment and early mortality.

These factors are compounded by financial constraints, lack of trained personnel, and inconsistent drug supply.[1][3-4]

Success Stories & Collaborative Solutions

APL is a model for successful protocol adaptation in LMICs. The use of all-trans retinoic acid (ATRA) combined with anthracycline-based chemotherapy, supported by international networking and standardized guidelines, has led to remission rates and overall survival approaching those in high-income countries (2-year OS ~80%).[3][6]

What helps

Twinning programs, regional collaborations, and training initiatives have demonstrated improved outcomes by facilitating protocol adaptation, capacity building, and data sharing.[2][5][6]

Evidence-Based Approaches for Reducing Treatment Abandonment and Early Death in Leukemia

Comprehensive family support:
Cover treatment, transport, housing, and food to reduce abandonment (e.g., Malawi: 19% → 7%). [1]

Partnerships & twinning programs:
Connect local and international centers for shared training, protocol adaptation, and psychosocial care. .[2-3]

Patient navigation & case management:
Dedicated staff to track appointments and provide social support (successful in Côte d'Ivoire, Uganda). .[4]

Resource-adapted treatment protocols:
Use risk-based, less intensive regimens to reduce toxicity and deaths. [5-6]

Strengthen supportive care:
Improve infection control, transfusion access, nutrition, and early warning systems (PEWS). [4][6-7]

Prevent treatment delays:
Ensure timely care and adherence to therapy schedules. [2]

Family & community education:
Address misconceptions and alternative medicine influences to improve treatment completion.[4]

Patient 2 continuation

After several days in intensive care, **John's condition stabilizes** and he is diagnosed with **acute lymphoblastic leukemia (ALL)**, specifically a **PH-like subtype**, showing **CRLF2 overexpression** and a **JAK2 mutation**.

Once he is strong enough, John begins an intensive chemotherapy program (**AIEOP-BFM protocol**) that includes multiple drugs such as **peg-asparaginase** and **high-dose methotrexate**. He completes the first three phases (**induction**, **reinduction**, and **consolidation 1**)

At the end of this third course, his medical team reviews the results of a **minimal residual disease (MRD)** test, that turned to be **positive**.

The doctors decide that **a stem cell transplant** should be the next step in John's treatment plan.

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What might be the main reason the medical team recommended a stem cell transplant for John at this point?

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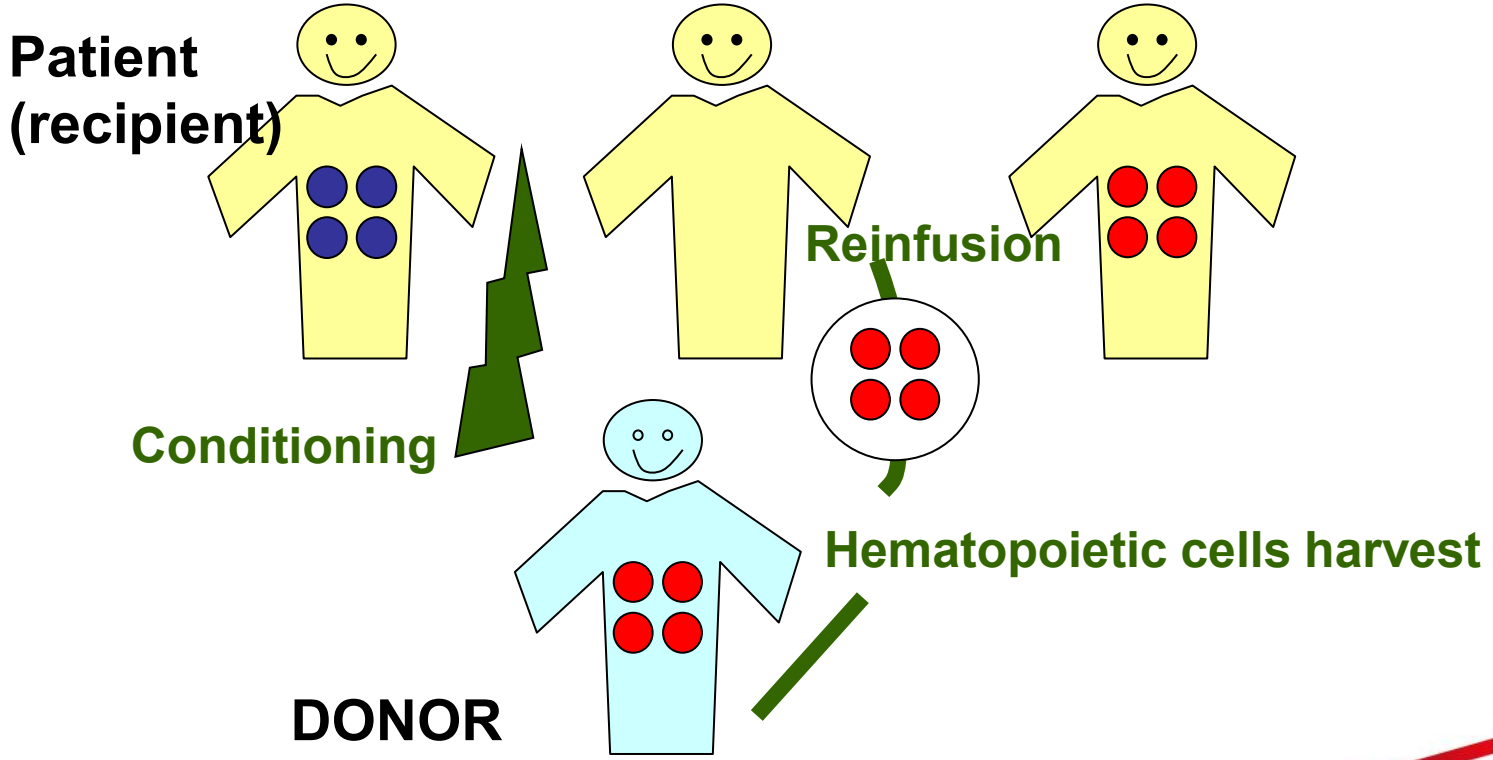
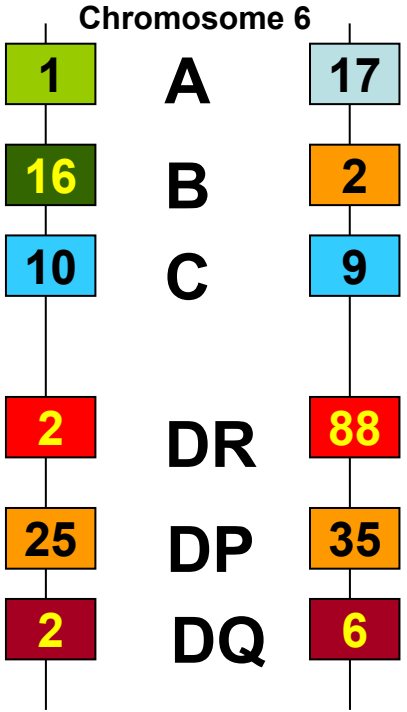
STEM CELL TRANSPLANTATION: INDICATIONS, TIMING, AND OUTCOMES

What's allo transplant



Donor compatibility



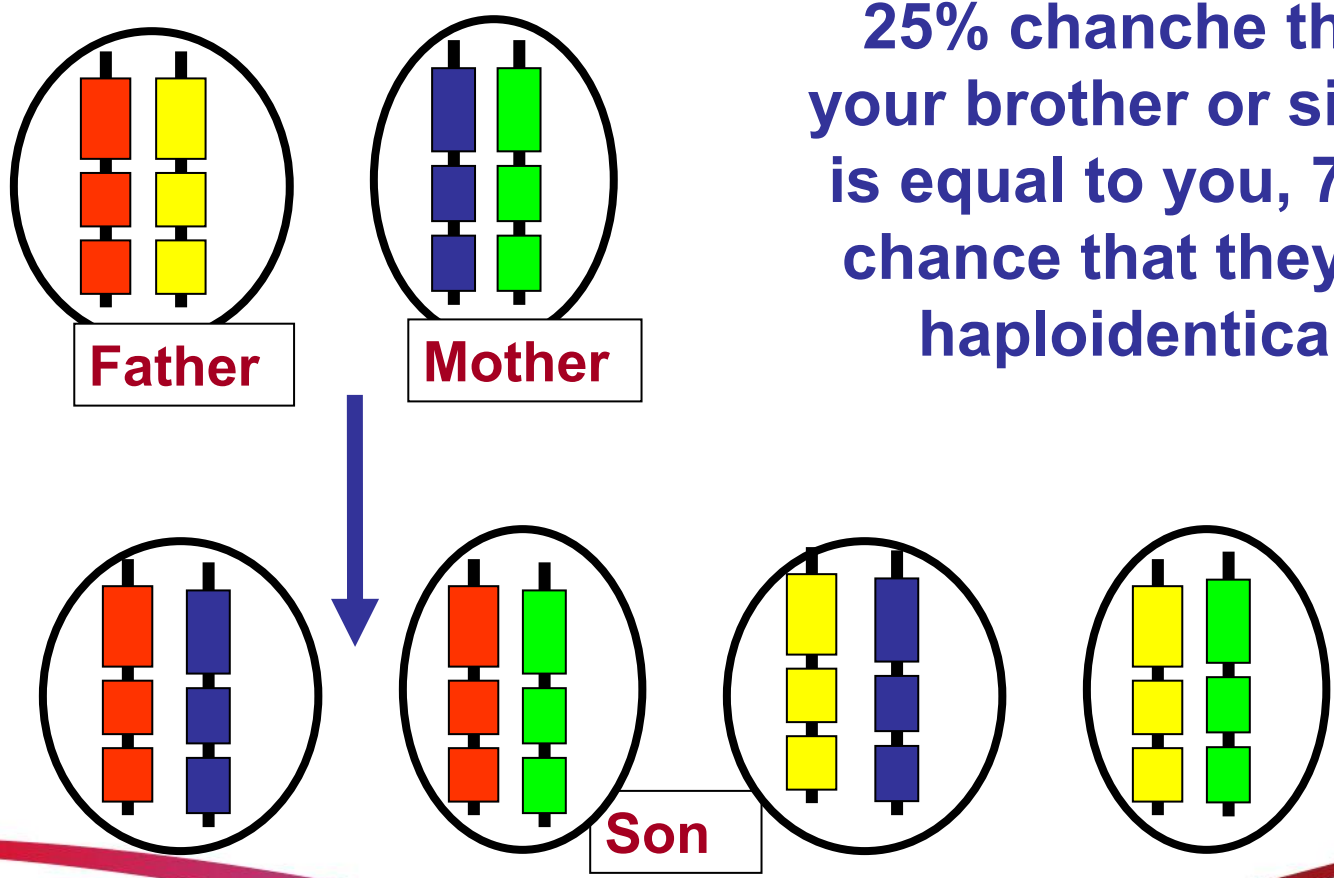
HLA genes

Help determine whether two people are a good **match for a stem cell transplant**.

There are **many possible variations** (called *polymorphisms*) in these genes → more than a hundred for each part of the HLA system across the global population.

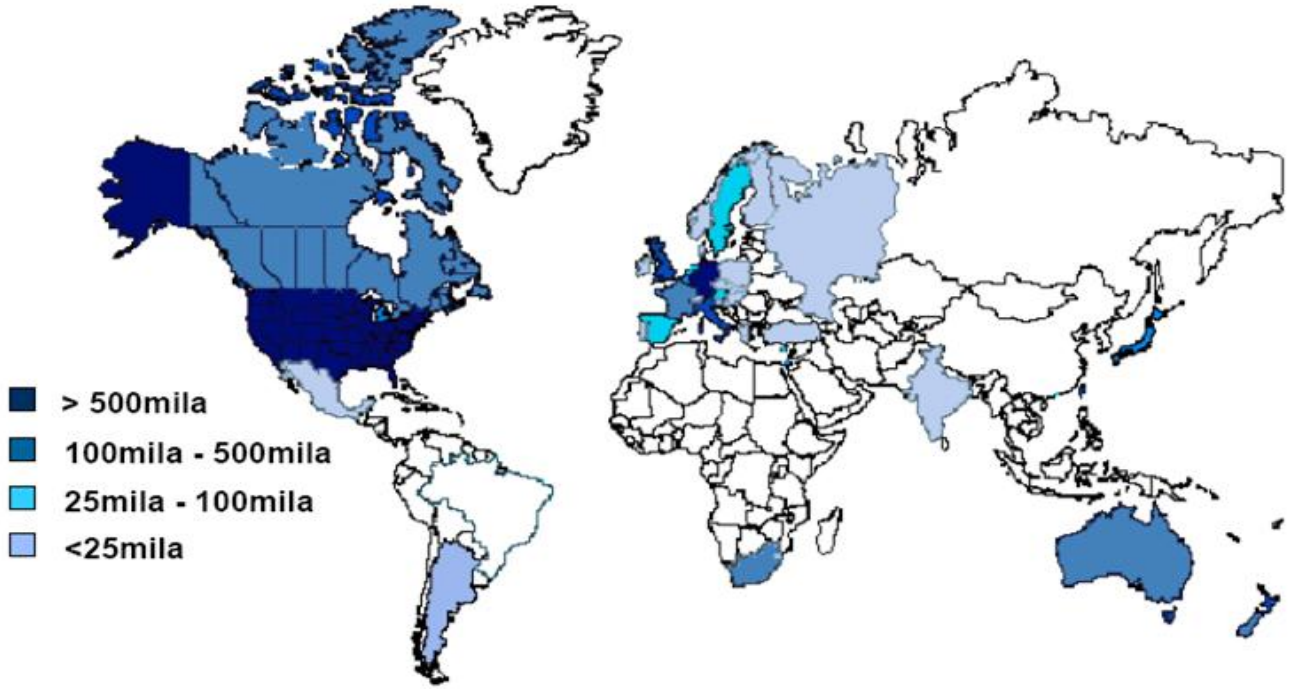
The **frequency of each variation** depends on a person's **ancestry or ethnic background**.

Familiar donor



25% chanche that your brother or sister is equal to you, 75% chance that they're haploidentical

Registry/unrelated donor



Dati tratti da BMDW/WMDA

What's the conditioning?

Therapy dose

Tumor

Hematotox

Transplant Conditioning

Or none

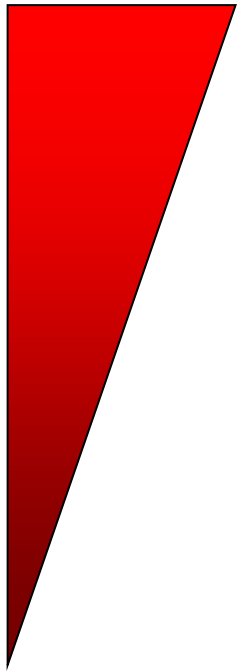
Aplasia

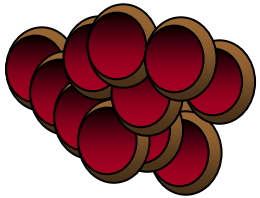
AML Induction

Severe Cytopenia

Lymphoma

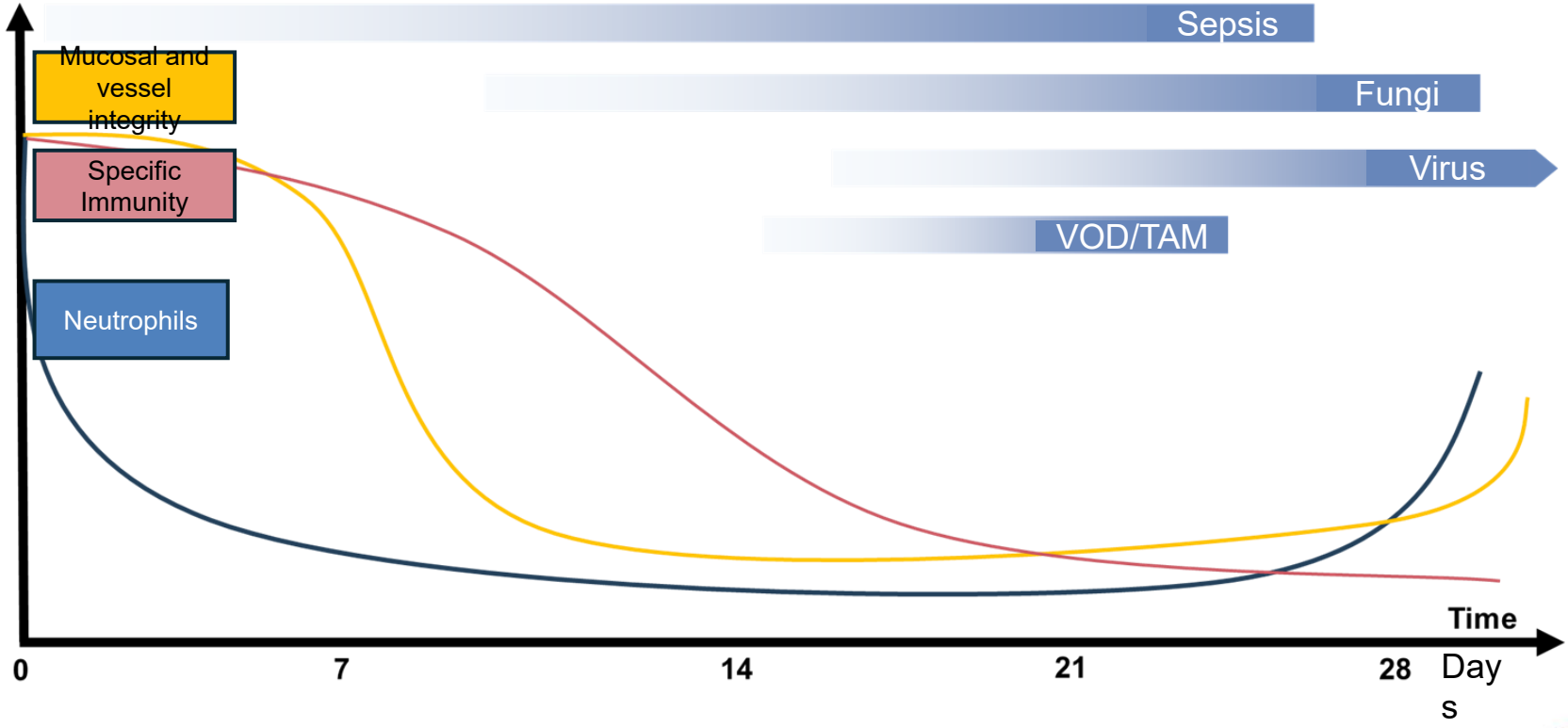
Mild Cytopenia





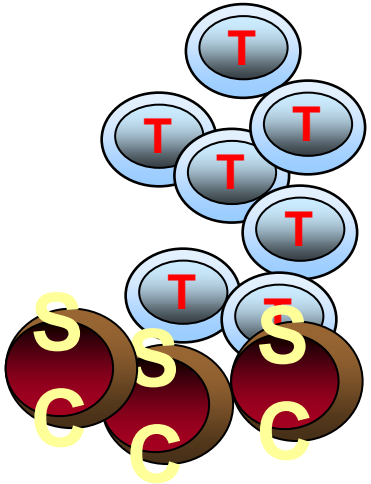
Thereafter HCT is not a surgical transplant, cells has homing system!

Early complications are due to conditioning



What's the GVHD? (and why HCT heal from leukemia)

BM/PBSC



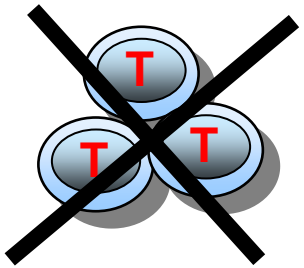
Graft vs host

GVHD

Graft vs leukemia

GVL

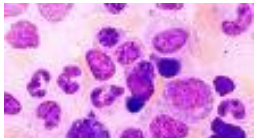
IMMUNOSUPPRESSION



Ciclosporin
Tacrolimus
Mofetil Micofenolate
Monoclonals

Liver Transplant

Last for the entire life



Hematopoietic cell T.

Last 3-9 months

ACUTE GVHD

Skin

Rush

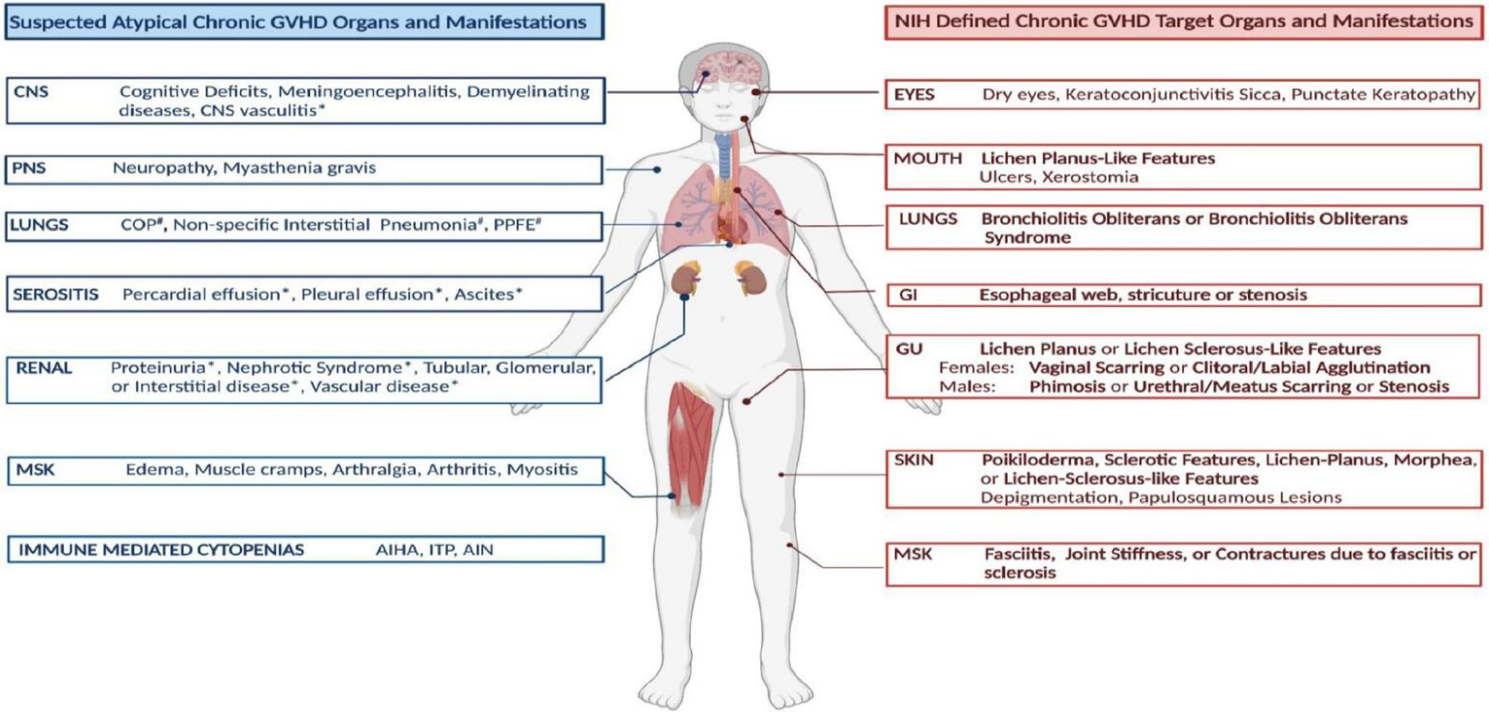
Bowel

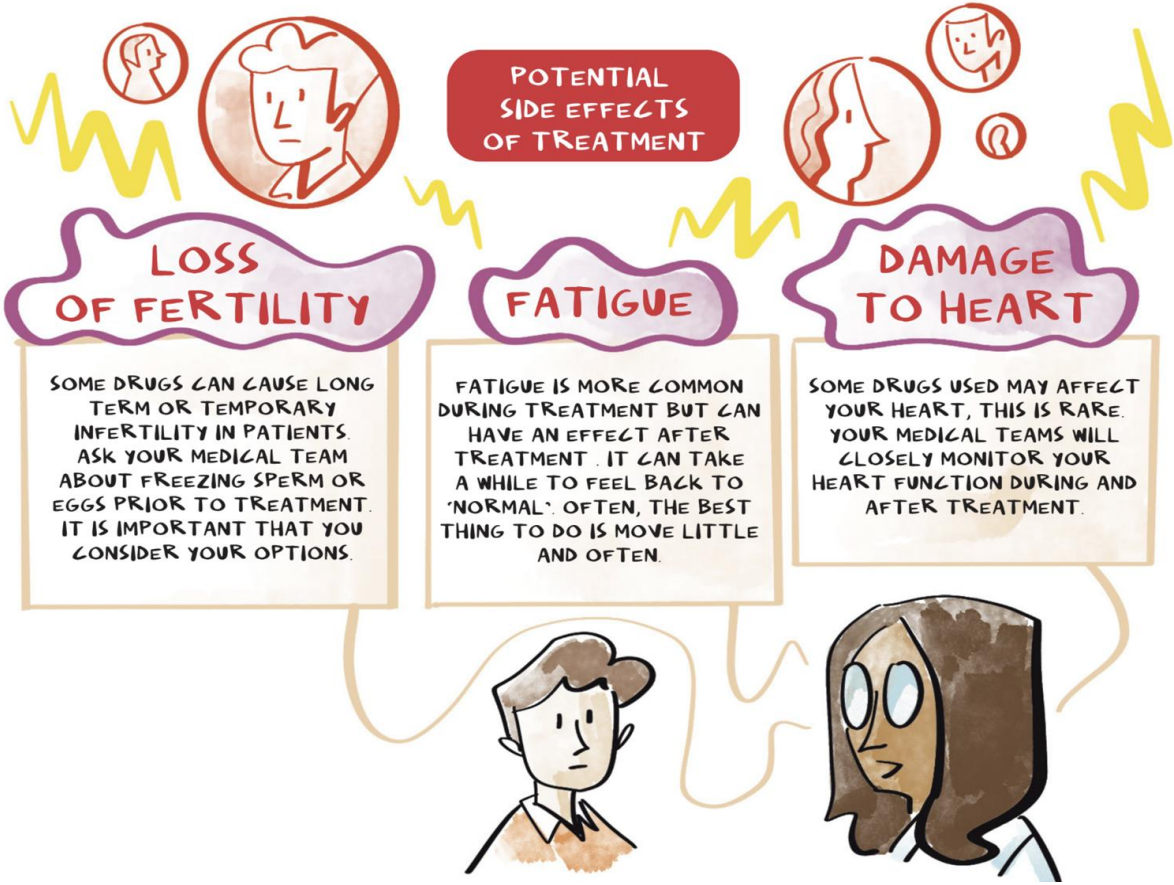
diarroea

Liver

Bilirubin increase

CHRONIC GVHD




POTENTIAL SIDE EFFECTS OF TREATMENT
LOSS OF FERTILITY
SOME DRUGS CAN CAUSE LONG TERM OR TEMPORARY INFERTILITY IN PATIENTS. ASK YOUR MEDICAL TEAM ABOUT FREEZING SPERM OR EGGS PRIOR TO TREATMENT. IT IS IMPORTANT THAT YOU CONSIDER YOUR OPTIONS.
FATIGUE
FATIGUE IS MORE COMMON DURING TREATMENT BUT CAN HAVE AN EFFECT AFTER TREATMENT . IT CAN TAKE A WHILE TO FEEL BACK TO 'NORMAL'. OFTEN, THE BEST THING TO DO IS MOVE LITTLE AND OFTEN.
DAMAGE TO HEART
SOME DRUGS USED MAY AFFECT YOUR HEART, THIS IS RARE. YOUR MEDICAL TEAMS WILL CLOSELY MONITOR YOUR HEART FUNCTION DURING AND AFTER TREATMENT.

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Audience Q&A

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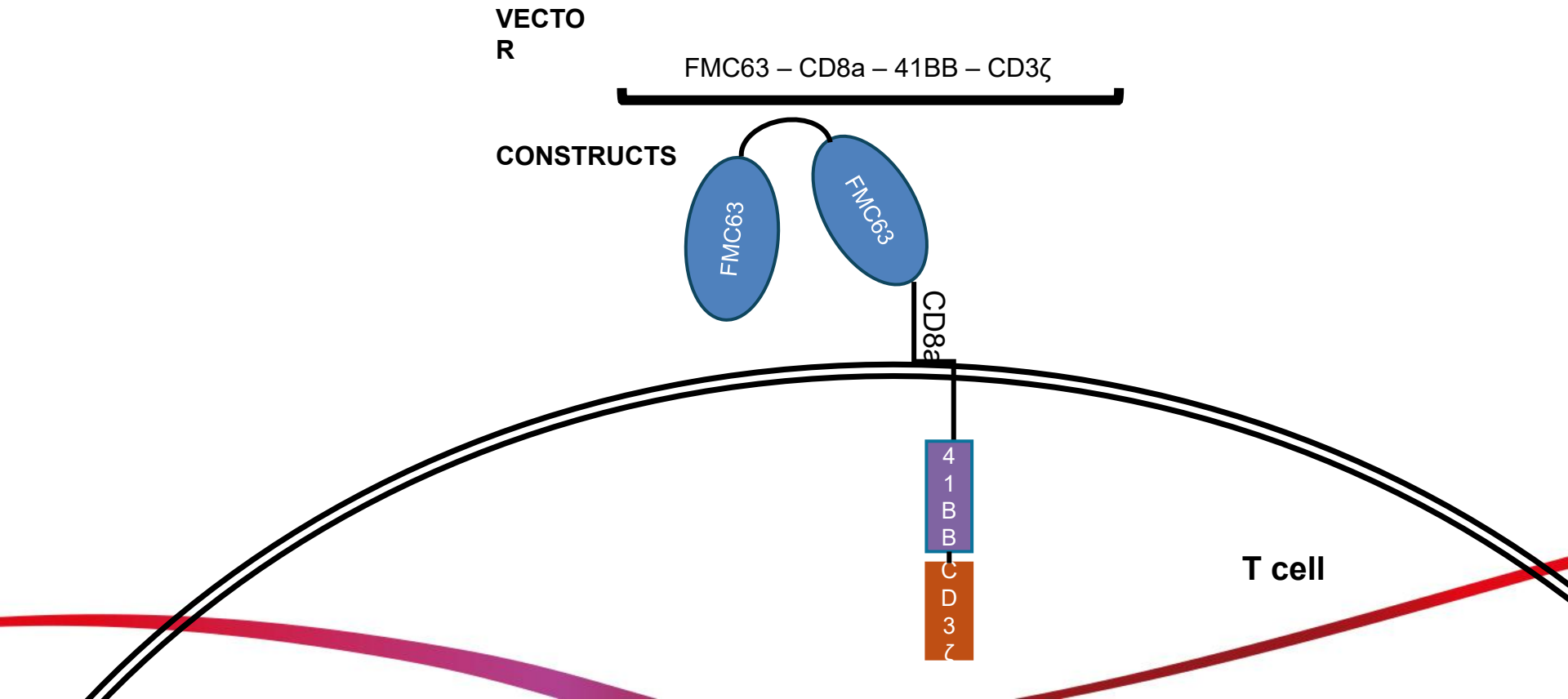
WHAT'S AHEAD: CELLULAR THERAPIES, PROMISING DRUGS AND CLINICAL TRIALS TO WATCH

But one question obsessed him: did his medical treatments work? Too often, he wrote, “**I had no idea whether I was doing more harm than good**.”

In his prisoner of war camp Cochrane was haunted by the fear that he had “shortened the lives of some of my friends”.

C. Craddock on A. Cochrane, the Economist

What's a CAR-T


VECTO
R
FMC63 – CD8a – 41BB – CD3ζ
CONSTRUCTS
FMC63
FMC63
CD8a
4
1
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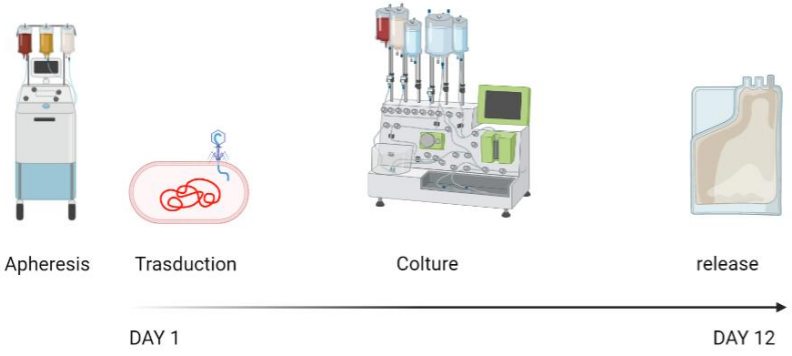
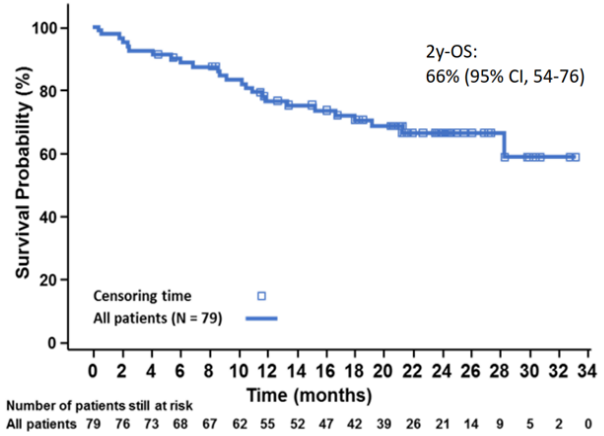
T cell

How we do a CAR-T

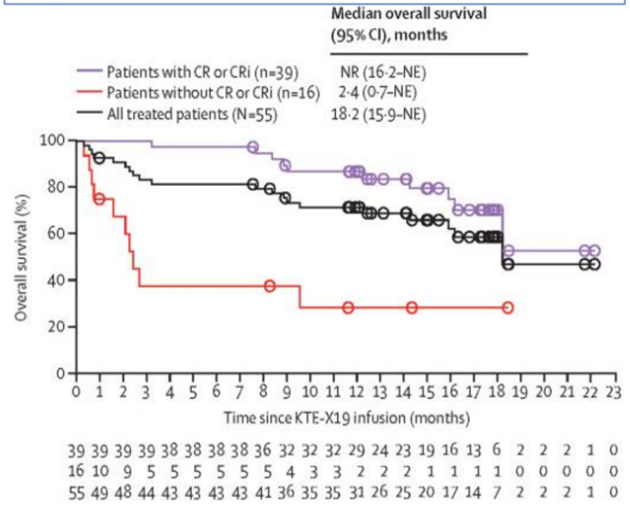


Long-term outcome after CD19 CAR-T in R/R B-ALL

ELIANA study[1]
Tisagenlecleucel, Kymria, Novartis
2nd relapse, 1st relapse after allo-HSCT
3-21 years
CD19/4-1BB/CD3z



ZUMA-3 study[2]
Brexucabtagene autoleucel, Tecartus®, Gilead)
R/R B-ALL
18 years+
CD19/CD28/CD3z



1. Maude SL, N Engl J Med. 2018 Feb 1;378(5):439-448 + Grupp S, ASH 2018
2. Shah B, et al. Lancet. 2021 Jun 3;S0140-6736(21)01222-8

Safety of CAR-T

	ELIANA[1] N=79	CIBMTR[2] N=255	APHP[3] N=51
CRS grade, N(%)			
- any grade	51 (77.2%)	140 (54.9%)	30 (59%)
- grade ≥3	38 (48.1%)	41 (16.1%)	10 (20%)
Time to CRS, median (range)	7(2-20)	6 (1-27)	4.5 days (0-10)
Neurotox grade, N(%)			
- any grade	31 (39.2%)	69 (27.1%)	12 (24%)
- grade ≥3	10 (12.7%)	23 (9%)	4 (8%)
Time to neurotox, median (range)	8 (2-489)	7 (1-80)	7 (4-65)

- **Probable contributions: learning curve + difference in patient profiles**
- **No difference in real-world study between patients <18y and 18y+**

1. Maude SL, N Engl J Med. 2018 Feb 1;378(5):439-448
2. Pasquini MC et al. Blood Adv. 2020 Nov 10;4(21):5414-5424
3. Adapted from Dourthe ME, et al., Leukemia. 2021 Dec;35(12):3383-3393.

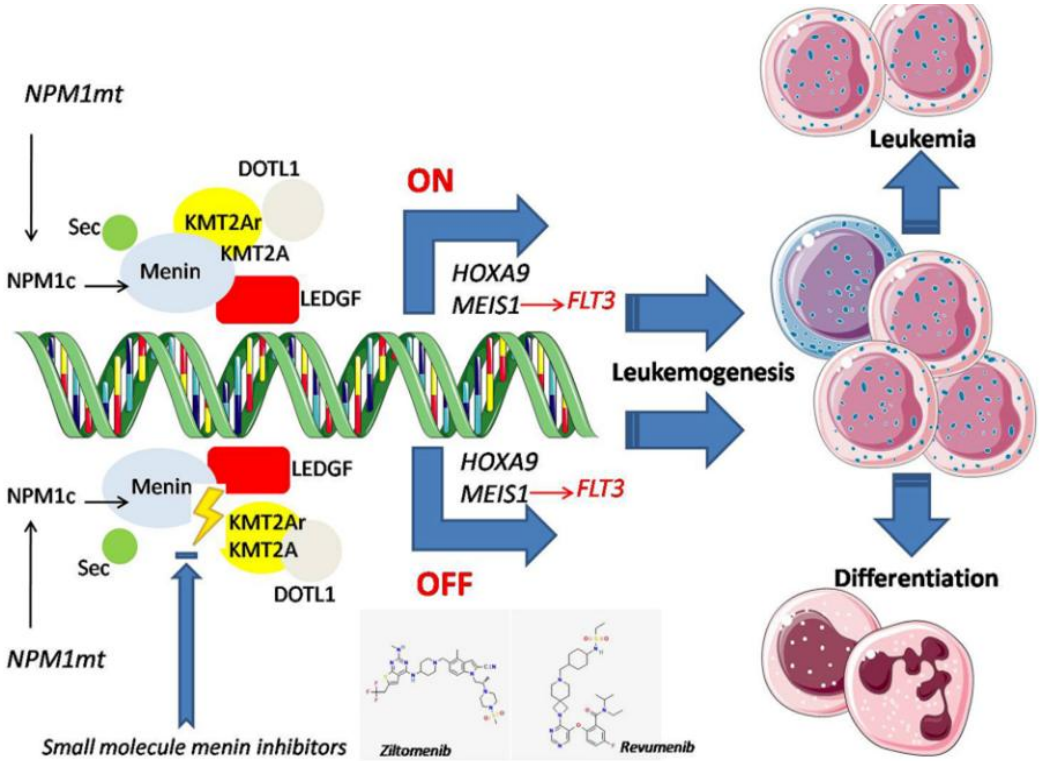
Recently, I saw a patient who drove six hours to consult with me. He was a former boxer, a light heavyweight, and had a leukemia that refused to be knocked out by a few rounds of chemotherapy.

I asked my patient if he was sure he wanted to pursue another treatment for his leukemia, given the vanishingly low chance that it would work.

“Nah doc, I’m not ready to throw in the towel yet. I’m still tough as nails!”

M. Seekeres, Washington Post

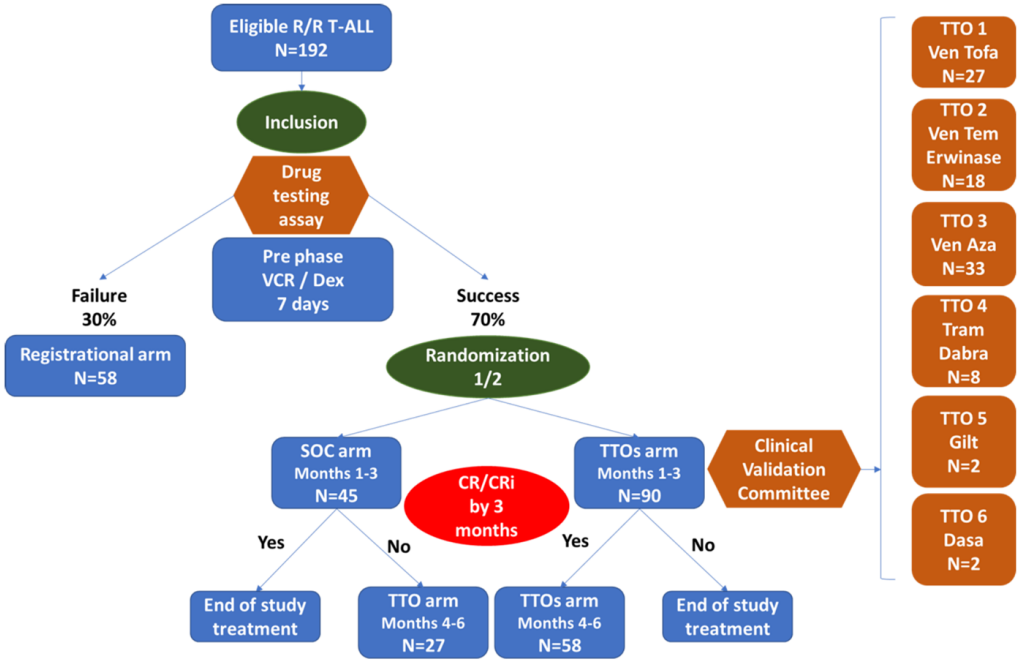
How menin inhibitors works



	Revumenib KMT2A (Issa, JCO 2024)	Revumenib NPM1 (Arellano, Blood 2025)	Ziftomenib KMT2A (Wang, Lancet 2024)	Ziftomenib NPM1 (Wang, Lancet 2024)	Bleximenib KMT2A, NPM1 + NUP98 (Searle, ASH 2024)	Enzomenib KMT2A (Zeidner ASH 2024)	Enzomenib NPM1 (Zeidner ASH 2024)	BN104 KMT2Ar, NPM1 + NUP98 (Wu, ASH 2024)
Number of patients	97	84	28	39	142 (83 KMT2A, 58 NPM1)	41	23	20
Prior Lines	2	2	3	3	2	3		3
Prior Venetoclax	72%	75%	71%	69%	NR	80%		100%
Prior HSCT	46%	?	43%	31%	36%	29%		20%
ORR	63%	47%	17%	45%	48%	65%	59%	88.9%
CR	17.50%		0%	35%				
CR/CRh	22%	23%	11%	35%	33%	30%	47%	33.3%
CRc	44%		17%	40%	38%			
MRD negativity	58% of CRc	?	100% of CR/CRh (2)	63% of CR/CRh				
TTR (mo)	0.9 (1.87 to CRh)	?	?	1.7	1.4	1	1.9	
DOR (mo)	4.3 (6.4 CR/CRh)	4.7 (CR/CRh)	2.1 (CR/CRh)	7.7	6	NR	7	?
Bridged to HSCT	33% (of responders)	16%	?	15%	14%	34%	12%	22.2%
OS (mo)	8		5.4	5.6				
DS	27%	?	39%	20%	19%	11%		10%
QTc	29%	?	0%	0%	NR	1%		10%
Thrombocytopenia	23%	?	11%	20%	10%	21%		?
Febrile Neutropenia	40%	?	27%	22%	3%	23%		15%

Courtesy E.Searle

EWALL-TARGET « pragmatic » trial



Courtesy N. Boissel

Investigational agent / approach	Reference
Subcutaneous blinatumomab (SC)	EHA 2025, Jabbour et al., Abstract S112.
Obecabtagene autoleucel (obe-cel, anti-CD19 CAR-T)	EHA 2025, Shah et al., FELIX post-hoc, Abstract S114.
Tuspetinib + venetoclax + azacitidine (TUSCANY)	EHA 2025, Mannis et al., Abstract S139.
Decitabine + venetoclax + quizartinib (triplet, FLT3-ITD AML)	EHA 2025, Yilmaz et al., Abstract S142.
Modular/adaptor CAR-T targeting CD33 (AML)	EHA 2025, Joechner et al., Abstract S126.
Oral decitabine/cedazuridine (DEC-C) + venetoclax (ASCERTAIN-V)	EHA 2025, Roboz et al., Abstract S135.
RVU120 (CDK8/19 inhibitor) + venetoclax (RIVER-81)	EHA 2025, de la Fuente et al., Abstract PS1509.
Pivekimab sunirine (PVEK, anti-CD123 ADC) in BPDCN (CADENZA)	EHA 2025, Pemmaraju et al., Abstract S141.
Bexmarilimab (anti-Clever-1) + azacitidine in MDS (BEXMAB)	EHA 2025, Kontro et al., Abstract S178.
Lenzilumab + azacitidine in proliferative CMML	EHA 2025, Thomas et al., Abstract S179.
Trem-cel (CD33-deleted HSC transplant) + GO maintenance	EHA 2025, Koehne et al., Abstract S144; ClinicalTrials.gov NCT04849910; linked to VCAR33 NCT05984199.
Oral DEC-C + VEN + ivosidenib/enasidenib (IDH1/2)	EHA 2025, Marvin-Peek et al., Abstract PS1471.

Do not edit
How to change the design

Rethinking Research in Leukemia – Who Gets Access, and How?

ⓘ The Slido app must be installed on every computer you're presenting from

slido

ALAN
Acute Leukemia Advocates Network

AI & DATA SCIENCE: SHAPING THE FUTURE OF LEUKEMIA RESEARCH

Artificial intelligence - ChatGPT

Prompt:
“make a picture that represent the potential impact of AI on medicine”

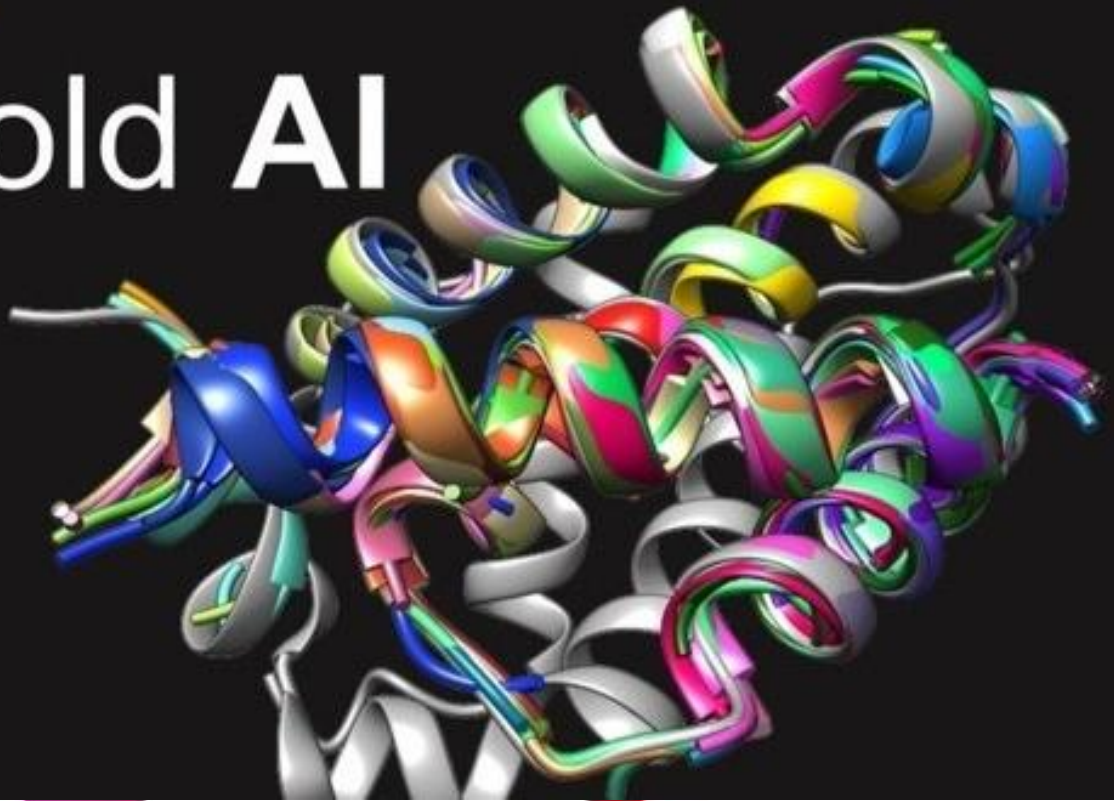
Result

ChatGPT provided a landmark-level, good looking, semi-original solution in 1 minute.

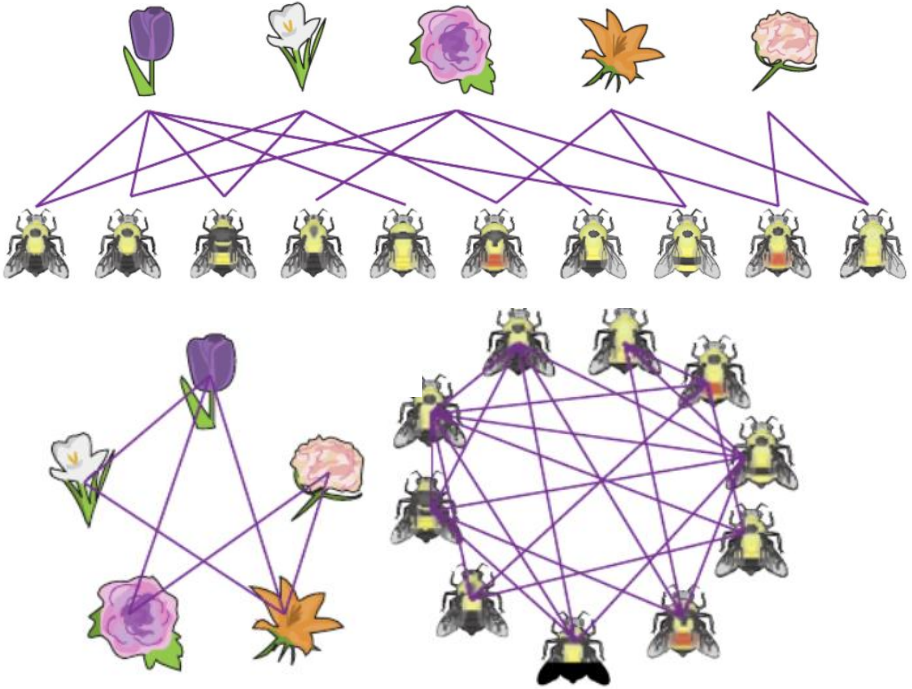
Can be useful for easy and repetitive task.

DeepMind

AlphaFold AI



Network medicine



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Artificial Intelligence: Promise, Limits, and Human Connection

ⓘ The Slido app must be installed on every computer you're presenting from

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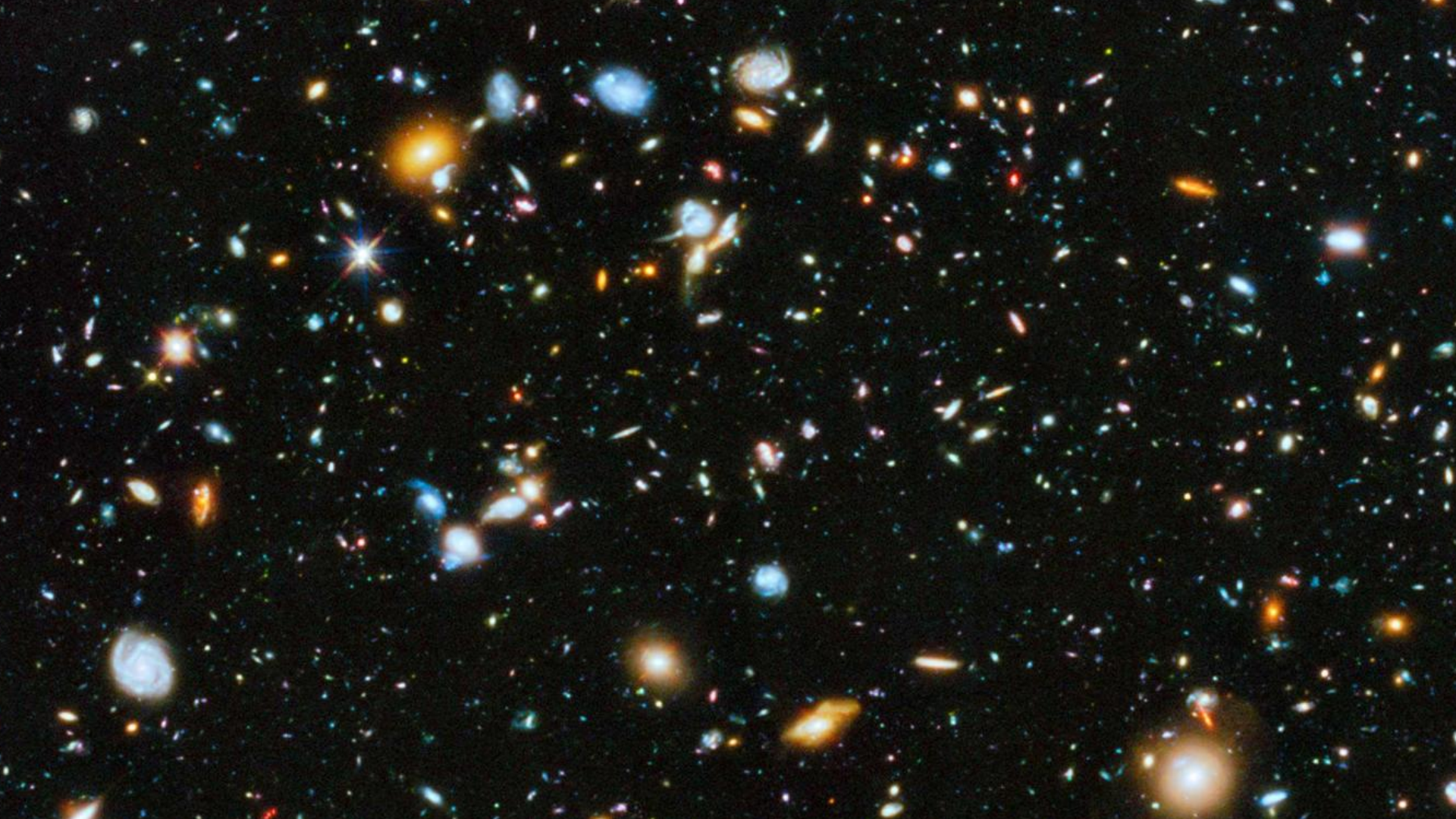


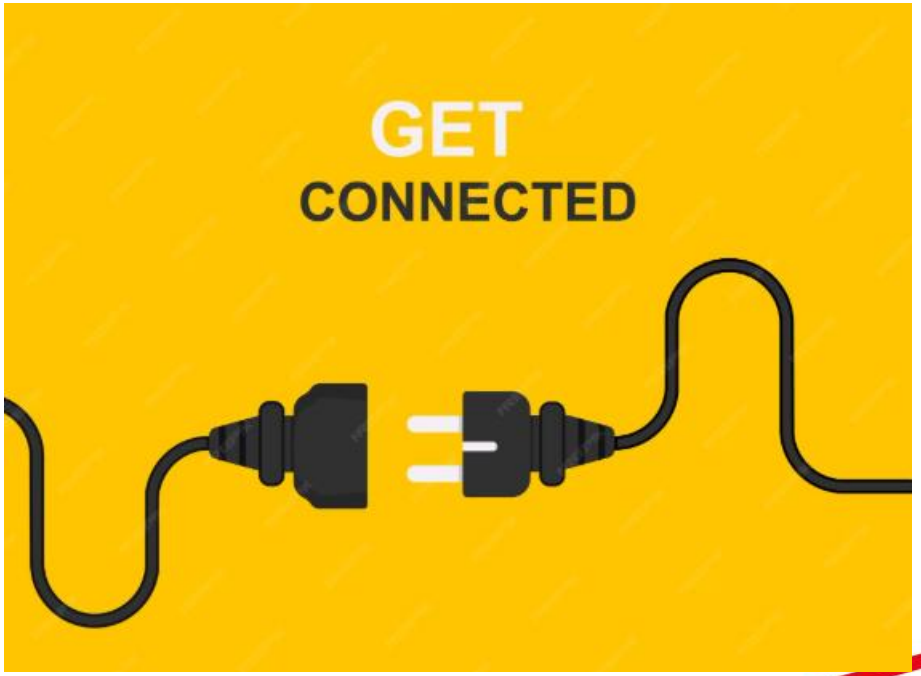
BREAK – BE BACK AT 4.30 PM !

Reconnect with your buddy

- **Dream board:** write on post-it(s) and put it/them on the wall

What is your biggest dream to drive change in advocacy?

- Take a picture with your buddy and post in **#ALANSummitpics**



TRANSITION TOWARD ADVOCACY: FROM EXPERIENCE TO ACTION

#ALANsummit

TO
FROM

KBDCA
Korea Blood Disease & Cancer Association

BUILDING AND ADVANCING THE PATIENT ASSOCIATION

From Concept to Influence

Chulhwan Lee, Founder / Secretary General

KBDCA
Korea Blood Disease & Cancer Association

Contents

01 PERSONAL JOURNEY

02 FORMING THE PATIENT GROUP

03 GROWTH & KEY ACHIEVEMENTS

04 FUTURE DIRECTIONS

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- Legal Incorporation
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- Major Programs
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- Expansion
- Strengthening
- Building Staff Capacity

Personal Journey

ABOUT THE SPEAKER

The journey of Chulhwan Lee, founder of KBDCA, **began in 1993 with a diagnosis of Acute Myeloid Leukemia (AML).**

After achieving remission through extensive treatment, including multiple rounds of chemotherapy and a resection for a severe lung infection, **his personal battle revealed the critical lack of organized patient support.**

His personal experience as a Leukemia patient motivated him to **establish the KBDCA in 2003.**

The organization has since become a major driving force in patient aid, **allocating over US$78 million per year** toward supporting those with blood disease and cancer.

DIAGNOSIS AND TREATMENT

AML Diagnosis *(Sep 1993)*

- Frequent Colds, Night Sweats, Fatigue, Shortness of Breath, Red Spots on calf

Chemotherapy *(Sep 1993 - Mar 1994)*

- 1st Chemo: Remission Failure
- 2nd Chemo: Partial Remission
- 3rd Chemo: Complete Remission

AUTO-HSCT PREPARATION AND LUNG SURGERY

Preparation for Auto-HSCT *(May 1994 - Feb 1995)*

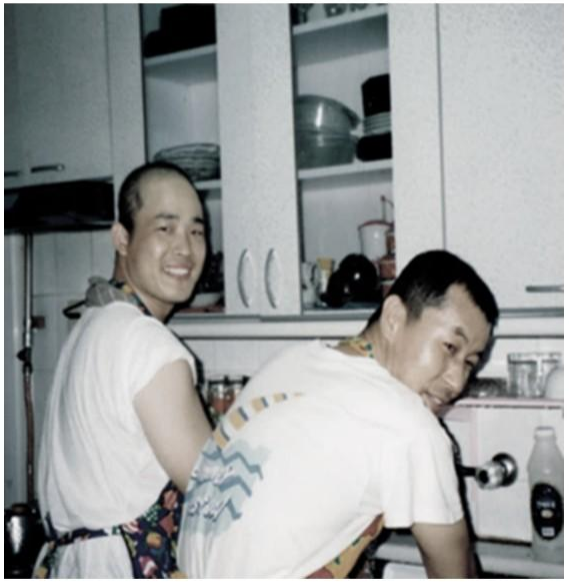
- 4th Chemo with 1st Stem cell harvest
- 5th Chemo with 2nd Stem cell harvest
- 6th Chemo (Maintenance)
- 7th Chemo (Maintenance)

Lung Surgery *(Jun 1995)* - Resection for Fungal Infection

Auto-HSCT Postponed *(Aug 1995 - Present)*

- Transplant postponed after bone marrow test
- Heavy costs for transplant preparation

MEMORIES OF TREATMENT



◀ **During Treatment**
(with the late Mr. Park, cofounder of an earlier Patient Support Group)

◀ **In-Hospital Treatment**

▲ **Family Photo**
(Family Trip after Chemotherapy)

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MOTIVATION AND ACTION

Motivation

- Patients and families face secondary burdens:
  lack of information, social isolation, and gaps in the medical system
- Personal Motivation derived from the fear of relapse
- Persistent persuasion from Mr. Park, a fellow patient (later co-founder)

Patient Advocacy Group

A non-profit organization of patients, families, clinicians, and advocates, dedicated to **information sharing, patient rights advocacy, policy improvement, and public awareness**

KEY FUNCTIONS

Information	Awareness	Advocacy	Emotional Support	Economic Support
• Treatment • Hospitals • Medication	• Campaign • Media • Education	• Requests for Policy • Change to the Government	• Counseling • Peer Group • Patient-Family Camp	• Treatment Cost • Living Expenditure

Forming the Patient Advocacy Group

LEUKEMIA PATIENT GROUP

Founded December 1995

Name Saebit Nurihoe - Group of People Overcoming Leukemia

Members

- Co-founders (3 persons)
- Working group (Full-time patient volunteers)
- Support group (Families, Medical advisors, Donor families)

Office Temporary Office in a suburb → Later in Seoul

CO-FOUNDERS

Dongha Park
(in memory)
(AML / Allo-HSCT)

- Emphasized the Need to Form a Patient Group
- Advocacy Activities
- Fundraising

Chulhwan Lee
(AML / Chemotherapy)

- Administrative Tasks
- Volunteer Management
- Communication with the HCPs

Junggook Seo
(in memory)
(ALL/ Auto-HSCT)

- Provided Office Space
- Financial Contribution
- Emotional Support

KEY ELEMENTS

Reflect patient and family needs

- Regular patient meetings
- Programs with clinicians
- Advocacy for insurance coverage
  (Medication, transplants, etc.)
- Public awareness campaigns
- Bone marrow and blood donation campaigns

KEY ELEMENTS

Minimize full-time staff, maximize volunteers.

1. **Full-time Staffs**
   - Accounting Management
   - Accounting

2. **Patient Volunteers** **Teams Organized per Program*
   - Medical Seminars
   - Blood Donor-Patient Matching Program
   - Member Management
   - Outdoor Programs (Hiking Club, Cultural Trips, Bone - Marrow Donation Campaign)
   - Counseling (Phone, In-person)

KEY ELEMENTS

Efficient Management

- Full-time staffs (Unpaid for 1 year)
- Donation (Patient Families)
- Support from Clinicians (Pharma companies)
- Support from organizations (Fundraising groups)
- Special Donations

CHALLENGES & SOLUTIONS

Challenges

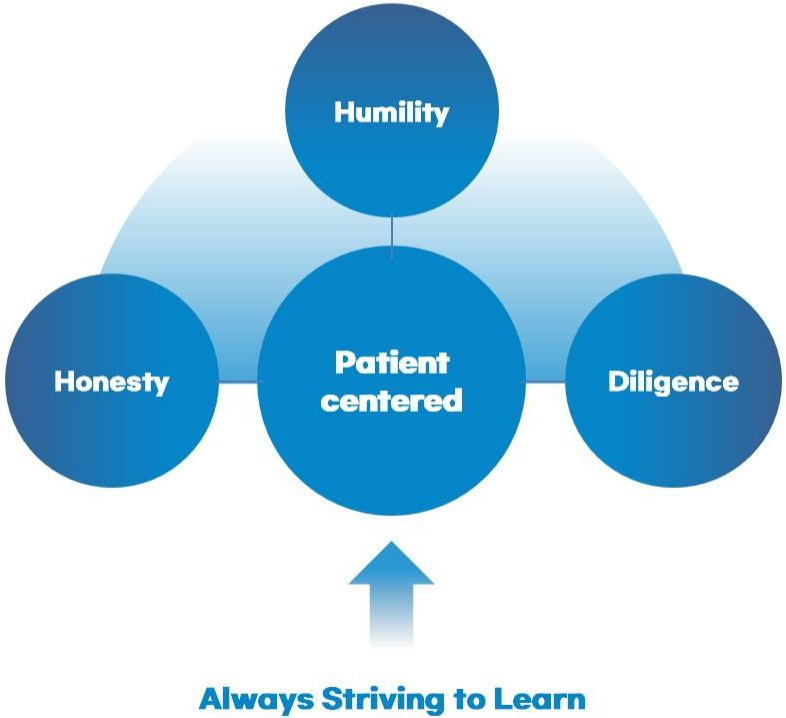
- Lack of Full-time Staff
- Difficulty Securing Stable Funds
- Limitations in Organized Activities
- Low Social Recognition
- Health Management Challenges

Solutions

- Volunteers (Dedication)
- Patient Families (Engagement)
- Clinicians (Support & Encouragement)
- Staff (Commitment)
- Family members (Support)

Operating the Patient Group

VALUES



WORKING WITH MEDICAL PROFESSIONALS

MAINTAINING GOOD RELATIONSHIPS WITH HCPS

Building Trust

- Authenticity
- Tangible Results
- Continuity
- Humility (Behind the scene)

Outcomes

- Support from Pharma companies
- Patient and Family Participation
- Enhanced Social Credibility
- Financial Stability

Operating the Patient Group

MAJOR ACTIVITIES

- Monthly Newsletter Publication
- Patient-Family Meeting
- Counseling (Phone / In-person)
- Platelet Donor-Patient Matching Program
- Bone Marrow Donation Campaign
- Advocacy for Patient Treatment Environment
  (Support for uncovered Drug costs / Awareness Campaigns)

새빛 누리회 제 1호

<백혈병을 이겨내는 사람들의 모임> 1996.1.15

Operating the Patient Group

MAJOR ACTIVITIES

Patient Family Class

Hiking Club

Cultural Trips

Programs with HCPs

Volunteer Recruitment

Donor Matching

Blood Donation Card

Blood Donor-Patient Matching Program

Bone Marrow Donation Campaign

Awareness Campaign

Public Awareness

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The Launch of KBDCA

PHASES

Birth

Patient self-help group

Dec 1995 - Dec 2002

Growth

Incorporation &
Organizational Development

2003 - 2012

KBDCA™
사단법인 한국혈액암협회

Maturity

Enhanced Programs & Services

2013 - 2025

VISION & MISSION

Vision

BUILDING A SUSTAINABLE AND SOUND PARADIGM OF PATIENT SUPPORT

Mission

Provide Treatment Information

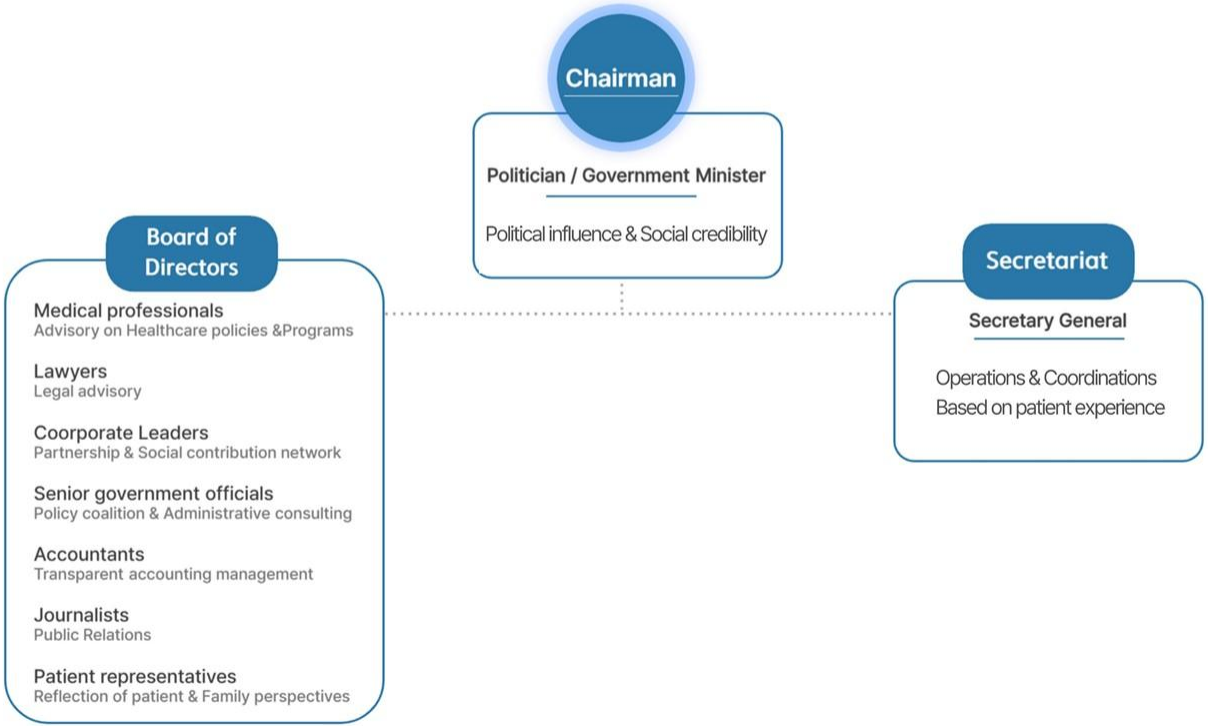
Better Treatment Environment

Inspire Patients' will to Fight Illness

Raise Public Awareness

Governance

Pursuing Publicity, Reliability, Sustainability, and Operational Efficiency



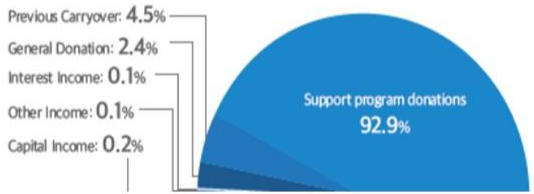
FINANCE & STRUCTURE

Finance (2024)

Total income

USD 78,512,000

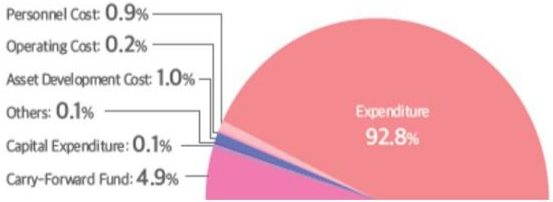
(1 USD = 1,400 KRW) USD)



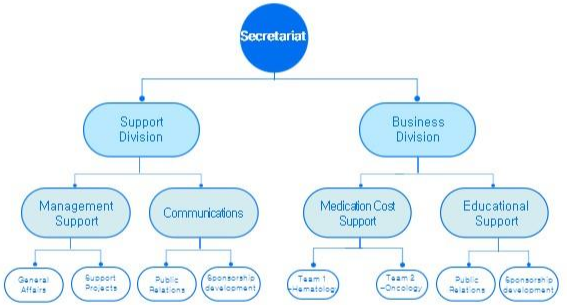
Total expenditure

USD 78,512,000

(1 USD = 1,400 KRW) USD)



Structure (28 Staffs)



MAJOR PROGRAMS (FINANCIAL AID)

Treatment Support

USD 107K - 179K / yr

Medication Cost Support

USD 71M - 86M / yr

Blood Donation Card Support

USD 29K - 36K / yr

MAJOR PROGRAMS (EDUCATION)

Lectures by the advisory medical team on the latest medical and clinical information.

Offline

Medical Mentoring

- Medical Lecture
- Individual Counseling
- Patient Mentoring

Hope Solution (KBDCA)

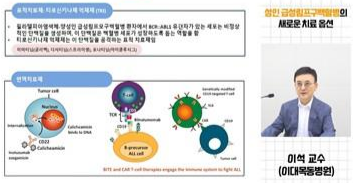
- Medical Lecture
- Open Counseling
- Networking

Open Lecture (Venue)

- Medical Lecture
- Open Counseling
- Networking

Online

Webinar



- Medical Lecture(Pre-recorded)

Talk Concert

- Panel Discussion

Phone Seminar

- YouTube Livestreams
- Phone Counseling

MAJOR PROGRAMS (PATIENT SUPPORT)

Supplies

Cosmetic wigs

Infection Control

BMT Kits(“Relief Box”)

Health Products

Body Care Products

Sanitizers

Protein Drinks

Support Programs

Rice of Love

Books

Clinical Trial Info

MAJOR PROGRAMS (EMOTIONAL SUPPORT 1)

Cultural Performances

Classical Music Event (“Going on Concert”)

Music Performance

Orchestral Performance

Outdoor Programs

Hope Hiking Club

Wellness Picnic

Overnight Camp

Support Programs

Patient Networking

Cooking Class

Mental Health Program

MAJOR PROGRAMS (EMOTIONAL SUPPORT 2)

Seasonal Newsletter

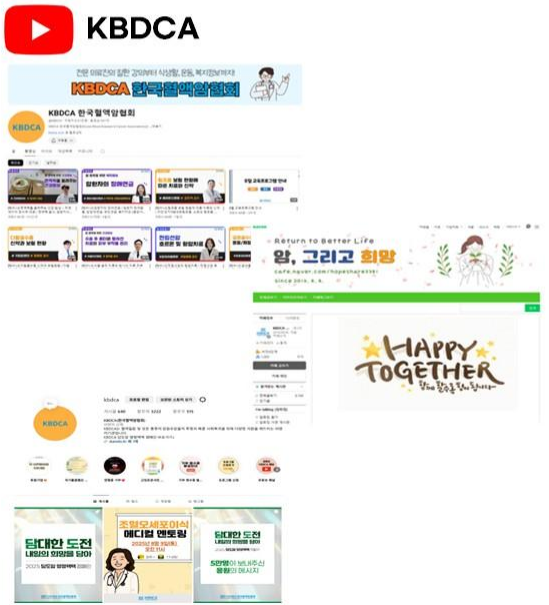
Medical Updates & Patient Stories

Disease Guidebook

Key Concepts & Treatments

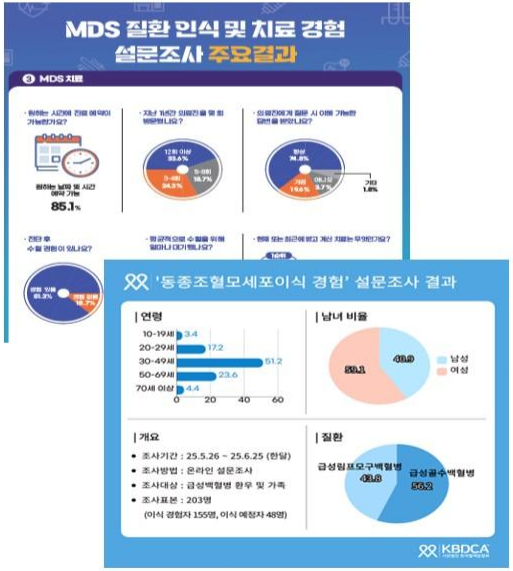
Online Program

(YouTube, Patient community, Instagram)



MAJOR PROGRAMS (RESEARCH, ADVOCACY)

Patient Survey



Advocacy

(National Assembly Forum, Press Conference)

International Exchange & Networking

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Future Direction

Expansion

- Expansion of Lecture Halls
- Support for Bone Marrow Donation
- Financial Assistance Programs

Strengthening Advocacy Activities

- Conducting Academic Research
- Developing New Policies
- Expanding Insurance Coverage
- Improving Treatment Environment

Building Staff Capacity

- Creating a Supportive Work Environment
- Rewarding Staff Achievements
- Implementing Staff Training Programs

KBDCA Korea Blood Disease & Cancer Association

Key Factors

1

Dedication & Passion

Co-founders
Staffs
Volunteers

2

Medical Professionals

Industry Support Secured

3

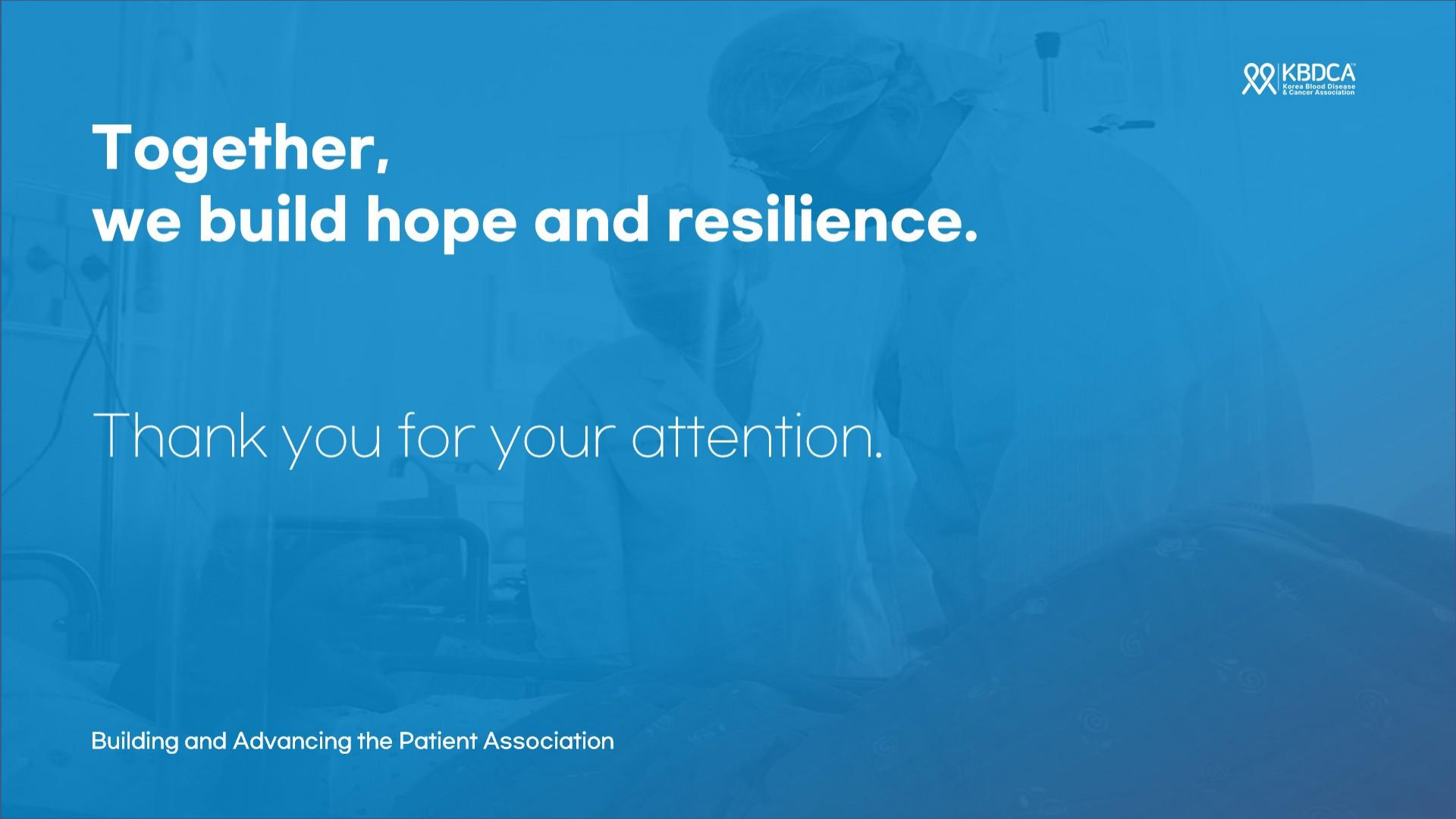
Patients

Consistent Support

4

Transparency & Accountability

Foundation of Trust



KBDCA
Korea Blood Disease & Cancer Association

Together,
we build hope and resilience.

Thank you for your attention.

Building and Advancing the Patient Association

ALAN

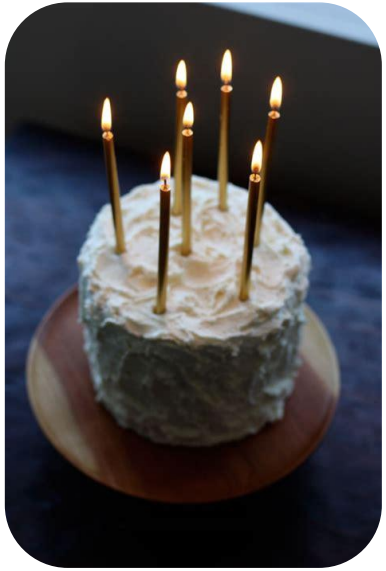
Acute Leukemia Advocates Network

TRANSITION TOWARD ADVOCACY – FROM EXPERIENCE TO ACTION

Anne-Pierre Pickaert – November 7, 2025

Hello I am Anne-Pierre

I celebrated my 11th year in January



of remission from Ph+ ALL
post bone marrow transplant

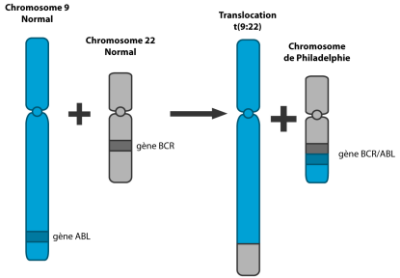
My patient journey timeline

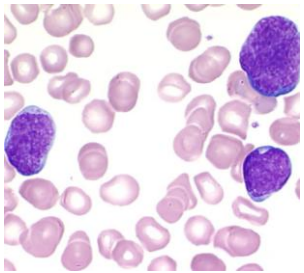
Things were going well for me

- I got married in May 2012
- By then, I had been building a career in healthcare for over 15 years
  - 10 years in public health and cancer prevention (public and non –profit sector)
  - 5 years in market access (pharmaceutical industry)
- I started a new job in April 2013 in market access

April 2013

But then my life took a bad turn





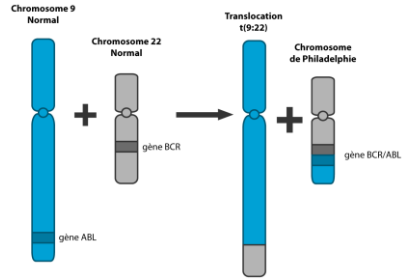
July 2013 nausea, increased sensitivity to strong smells, fatigue

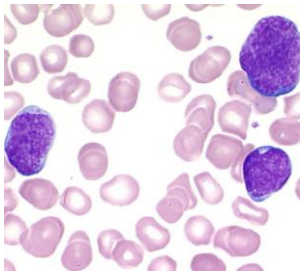
Aug. 2013 weight loss and shortness of breath over 50 000 lymphoblasts -> B ALL

Sept 2013 Philadelphia +
➔ Stem cell transplant (SCT)

Sept. – Dec. 2013 Induction & maintenance

I got a luckier escape than many





July 2013	nausea, increased sensitivity to strong smells, fatigue
Aug. 2013	weight loss and shortness of breath over 50 000 lymphoblasts -> B ALL
Sept 2013	Philadelphia + ➔ Stem cell transplant (SCT)
Sept. – Dec. 2013	Induction & maintenance
Nov 2013	Negative minimal residual disease
Jan. 2014	Conditioning for a 10/10 matched unrelated donor stem-cell transplant

Becoming an advocate

Becoming a patient advocate was never a part of any plans

September 2013

Becoming a patient advocate was never a part of any plans

Day 16
128 days before BMT

Paying it forward: volunteer

egmos
Entraide aux Greffés de Moelle Osseuse

Laurette Fugain
l'association qui lutte contre la leucémie

ALAN
Acute Leukemia Advocates Network

SFGM TC
Société Francophone de GREFFE DE MOELLE et de Thérapie Cellulaire

Paying it forward: Advisor

ALAN
Acute Leukemia Advocates Network

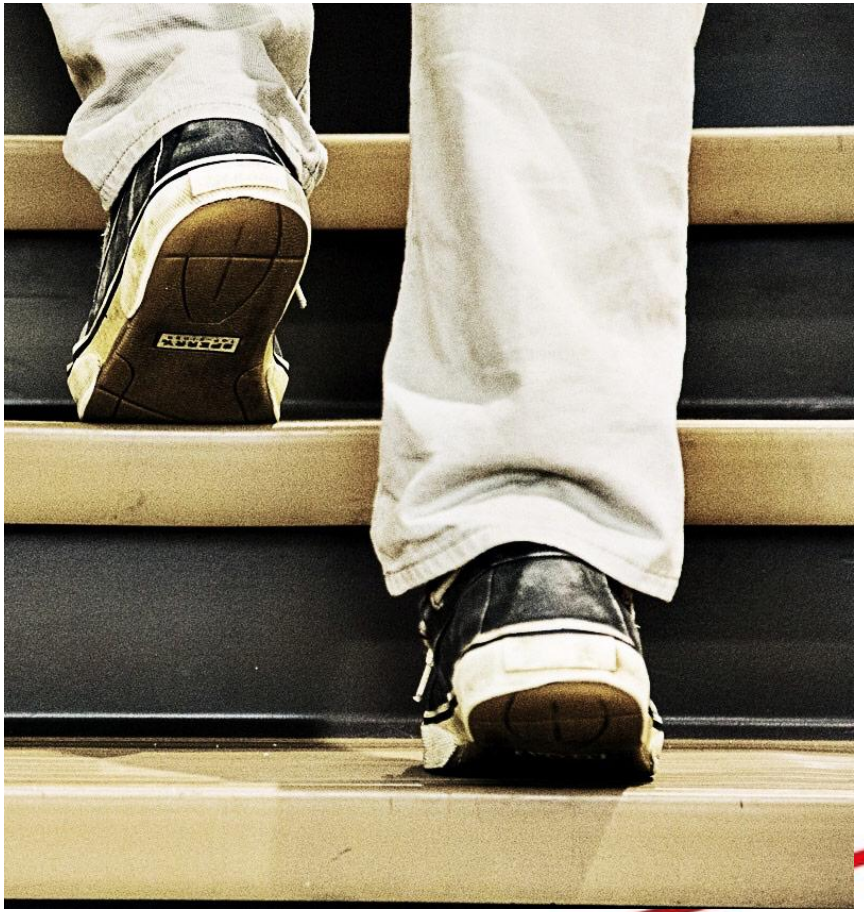
A concrete example of an outcome of my advocacy work

Advocated for setting and implementing a bone marrow donor self-sufficiency goal

Evaluation of Implementation of the Objectives and Performance Contract 2017–2020 of the French Biomedicine Agency (ABM).

Inclusion of a 25% bone marrow donor self-sufficiency goal in the 2022-2026 Bone Marrow Transplant Plan

Some lessons learned



Take nothing for granted

Every right we gain, every policy we influence, requires ongoing effort to maintain.

There is no finish line;
there's only the next lap.

ChatGPT

Take nothing for granted: a goal is as good as when it is met

Pays	France	Italy	Spain	Germany		UK		
Registries	FGM	IBMDR	REDMO	ZKRD	DKMS	Anthony Nolan	DKMS UK	Other
Total number of donors	411,000	521,000	516,000	2,521,000	7,998,000	931,000	1,063,000	492,000
Registration age limit	18-36 years old	18-36 years old	18-40 years old	17-55 years old	17-55 years old	16-30 years old	17-55 years old	
% self-sufficiency 2024 (*)	8%	24%	25%	82%[1] (60%[2])		26%		
% unrelated donors (**)	56%	52,50%	47%	79%		68%		
Year 2024								
Number of new donors	15,717	32,184	30,010	96,354	358,232	30,727	49,632	

(*) % of national patients who received an unrelated transplant from a national donor (excluding cord blood)

(**) % of allogenic transplants from unrelated donors (excluding cord blood)

[1] All German donors including DKMS

[2] Only DKMS Germany donors

Secure Your Own Well-being for Sustainable Advocacy

Advocacy is rewarding, as well as emotionally and physically demanding.

You can only help others effectively when you're secure yourself.

By caring for yourself, you ensure you can continue to care for others.

Keep up with the pace of scientific change

- Stay informed, stay ahead
- Monitor availability and accessibility of new treatments (as well as current ones!!)
- Learn from recent patient experiences and go beyond personal experience

Le Chat Mistral

THANK YOU!

In a nutshell

Marine Tullet

Data & AI passionate

Climbing, bivouac & hiking lover

… and advocate being member of ALAN Steering Committee!

It all started by being a carer...

...and an advocate for my brother in 2021

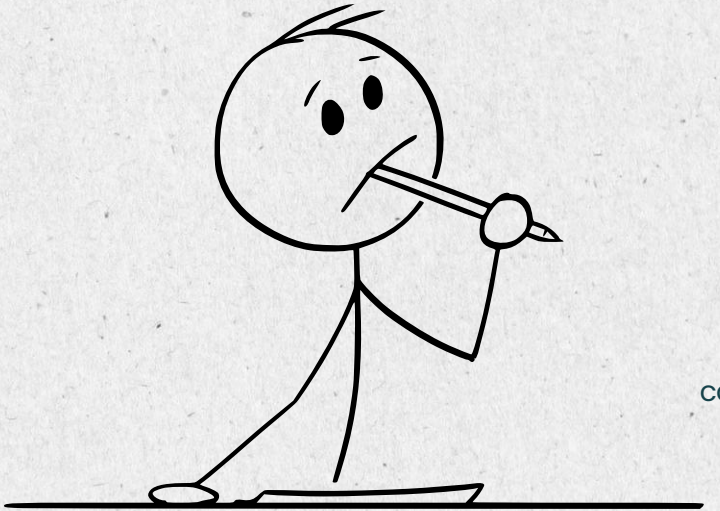
It ended up being an advocate.

“If the mountain feels out of reach today, start climbing it tomorrow.”

Walter Bonatti

Carolina Garcez

From Medical Student to Patient... to Maybe Doctor?



November 2025

E-mail
carolina.garcez.a.martins@gmail.com

My Medical Journey

2017
1

2018
2

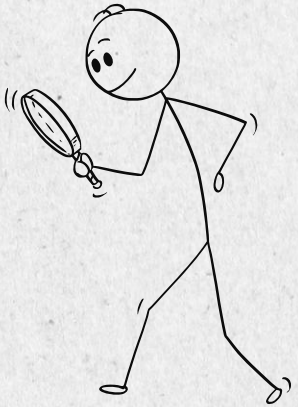
2019
3

2020
4

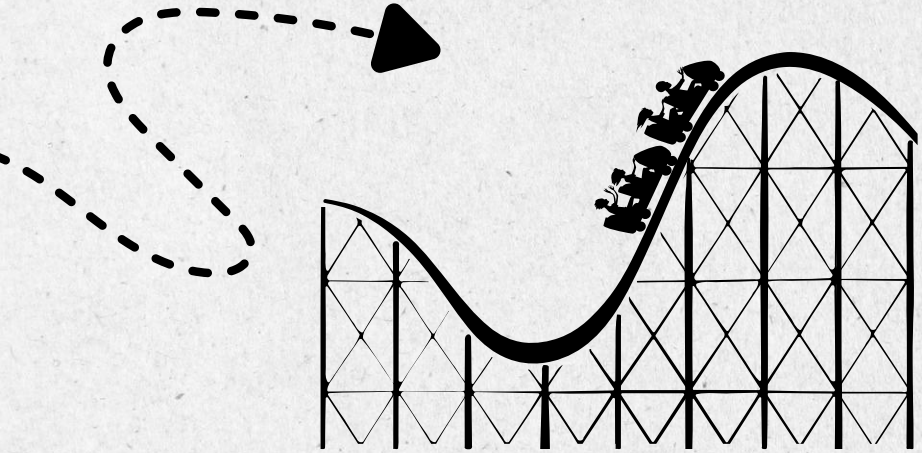
2021
5

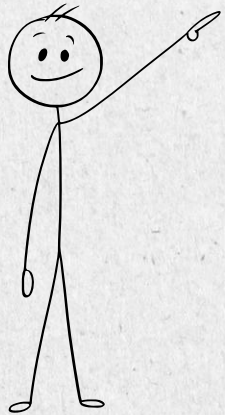
2022
6

FINISH

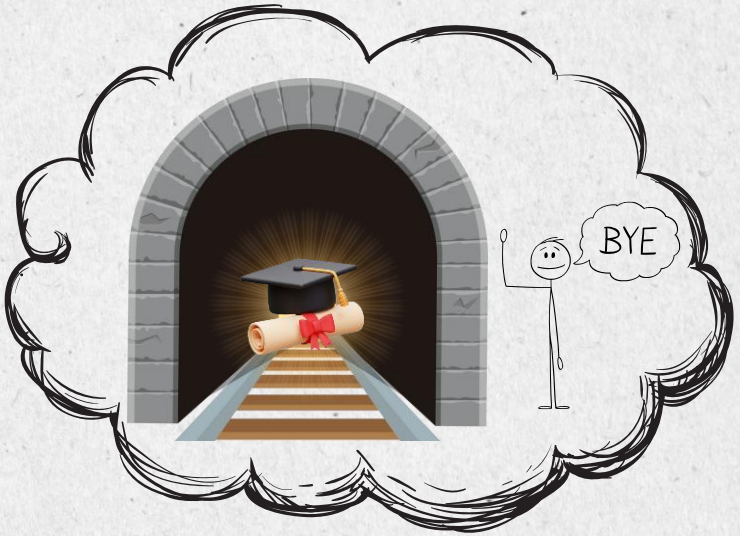


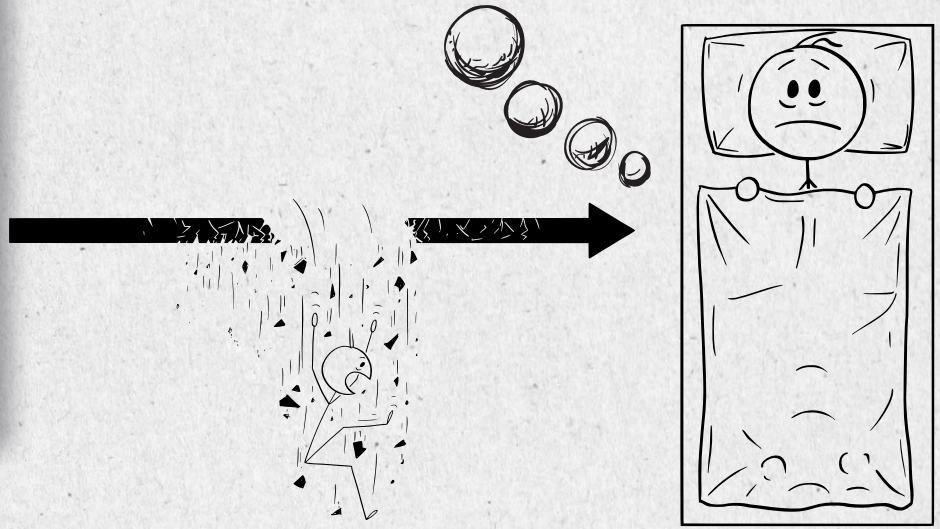
If you could zoom in on any random day of med school...





One ordinary day during my final year as a student...





#EUPATI
EUPATI
Education empowering patients to engage and partner with all stakeholders in medicines R&D

Próximos tempos só assim

Desespero? Sim

Nov 2022

“My worth depends on what I can do.”

“I know nothing about medicine. I need to study more.”

“The questions in medical exams are the hardest ones.”

“I need to know every reference value from blood tests.”

Fev 2023

“I feel useless.”

“Why do I suddenly know so much?”

“Those questions had right answers. Most of mine now don’t.”

“They seem to care more about the numbers than about me.”

Nov 2022

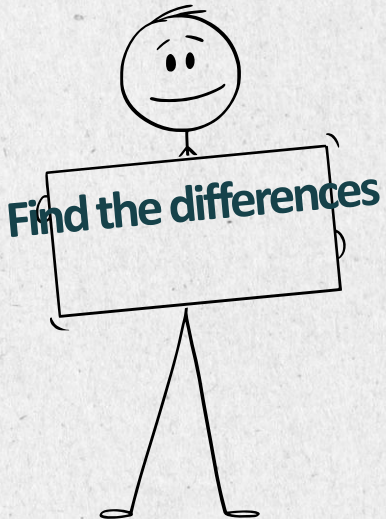
"Being a good communicator is very important for a doctor."

"I know I need to see the person, not the disease."

"Most of my classmates will be amazing doctors."

"We need to take care of the family too."

"Doctors give patients discharge and think the worst is over."



Fev 2023

"Some talk a lot and most don't truly listen."

"I've never felt so unseen."

"They don't even know how to talk to me anymore."

"Why is no one supporting my parents?"

"That can often be when the real struggle begins."

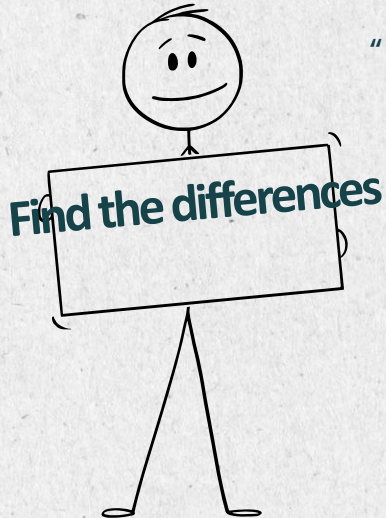
Nov 2022

“Good care comes from knowledge and skill.”

“Caring is so difficult.”

“Caring is understanding how someone feels.”

“There are difficult patients.”



Nov 2023

“Good care comes from presence.”

“Good care is easier than we think.”

“Caring is respecting and being there for how someone feels.”

“I am the difficult patient.”

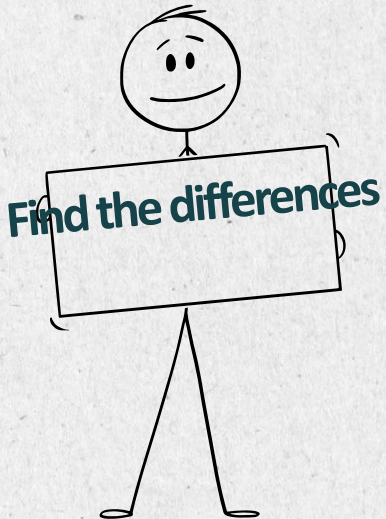
Nov 2022

"As a doctor I can only harm patients by not treating them or treating them wrong."

"We study life."

"Medicine was my dream, my identity."

"I'll be a reasonable doctor."



Nov 2023

"Well... guess what?"

"Why do they ignore so many aspects of life?"

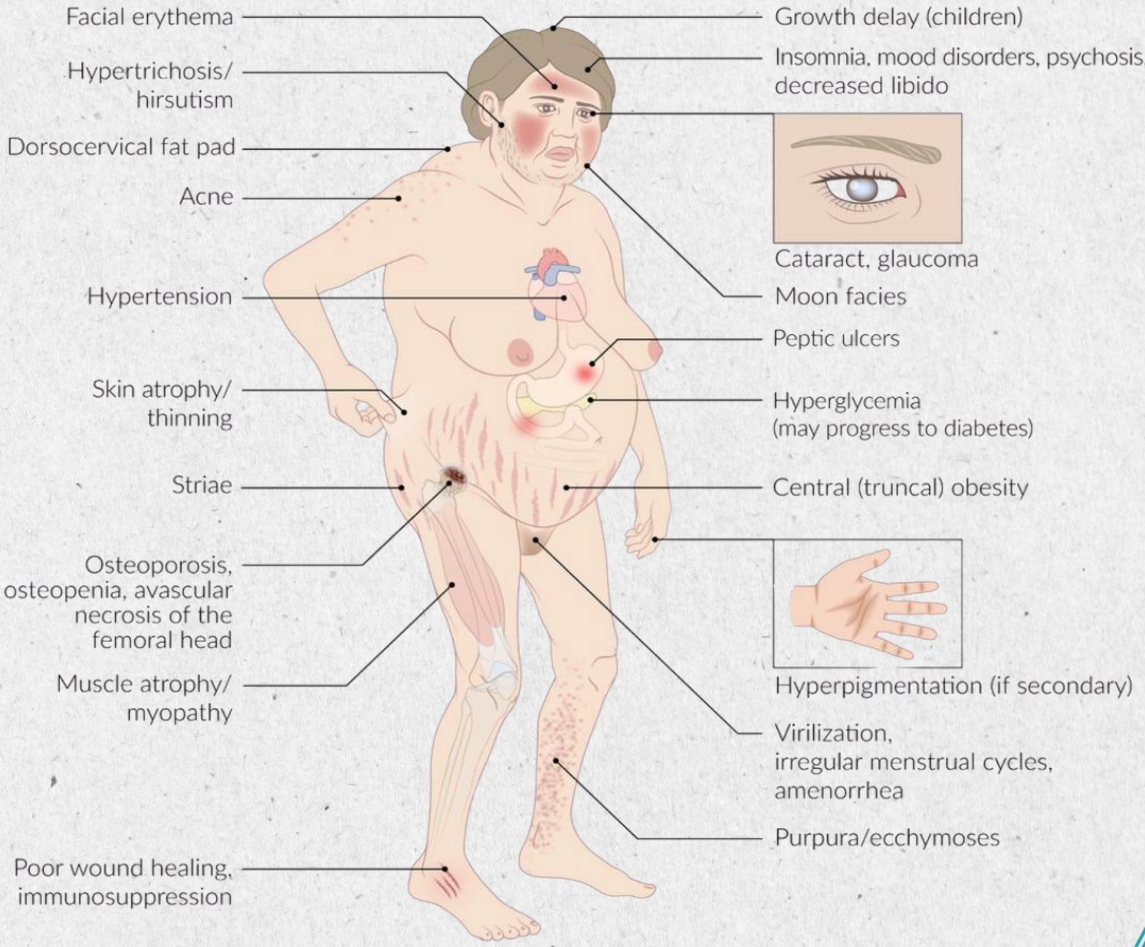
"Medicine became a place of pain, confusion, and disappointment."

"If I survive, I don't want to be a doctor."

Most people start medicine for the right reasons.

... To help.
... To relieve suffering.
... To heal.
... To make a difference.

So... What Went Wrong?


Facial erythema
Hypertrichosis/ hirsutism
Dorsocervical fat pad
Acne
Hypertension
Skin atrophy/ thinning
Striae
Osteoporosis, osteopenia, avascular necrosis of the femoral head
Muscle atrophy/ myopathy
Poor wound healing, immunosuppression
Growth delay (children)
Insomnia, mood disorders, psychosis, decreased libido
Cataract, glaucoma
Moon facies
Peptic ulcers
Hyperglycemia (may progress to diabetes)
Central (truncal) obesity
Hyperpigmentation (if secondary)
Virilization, irregular menstrual cycles, amenorrhea
Purpura/ecchymoses

AMBOSS

What We're Trained to See

We're trained…

…To recognize **patterns**.

…To **fit people into boxes**.

…To focus on what matches a diagnosis.

…To ignore what doesn't.

… To **live in our heads**,

because that's how you survive in medical school.

What We're Trained to See

We study bodies as if they were all the same...

...Yet we **barely study what it means to be human**.

We're trained to "see the person, not the disease"...

... But we often believe we **already know who that person is**.

What We're Trained to Say

We're trained…

… To ask **every "mandatory" question**.

… To allow silence, but **not for too long**.

… To recognize emotions, but **not our own**.

We practice communication.
Not connection.

This Goes Beyond Healthcare

It’s a reflection of our society.

Of how we live, how we relate to family, to friends, to colleagues…and, most of all, to ourselves.

What’s missing is presence.

When we’re truly present, the answers come.

The Next Chapter

I don’t know if I’ll become a doctor.

But I do know that I’ll keep learning what medicine really means.

Being a good doctor isn’t a formula.

Presence is not a skill.

It's a choice.

And our presence can inspire others to be present too.

… Maybe that's where true healing begins.

Thank You

November 2025

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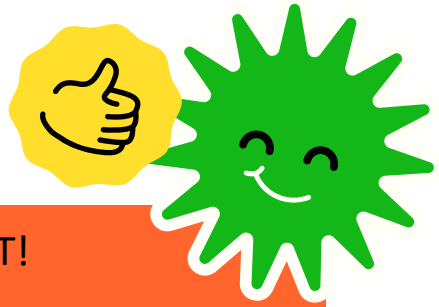
TOMORROW'S AGENDA



8.15 AM	Grounding
8.30 AM	Workshop: Advocacy in the acute setting
10 AM	May I borrow your buddy?
10.30 AM	Let's talk about data
11 AM	Turning insights into action
12.30 PM	Group photo
12.45 PM	Lunch

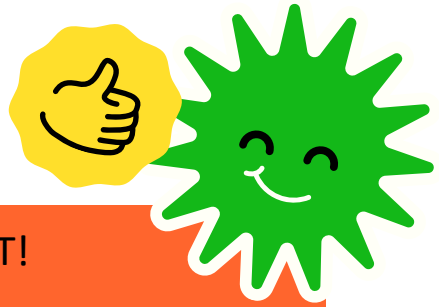
DON'T FORGET!

- We do not expect anyone to be an observer - Everyone is welcome and encourage to participate
- Activities proposed during the breaks are optional
- Bad english is the official language

TO-DOS

- Be on time !
- Keep your badge on
- Mute your phone and switch off your computer

TOMORROW'S AGENDA



1.30 PM	From Data Collection to Advocacy
2.30 PM	Turning Insights into Access
3.30 PM	Marshmallow challenge
4 PM	Workshop: Barriers to access
5.30 PM	Yoga with chair
7 PM	Dinner (hotel)

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- Activities proposed during the breaks are optional
- Bad english is the official language

TO-DOS

- Be on time !
- Keep your badge on
- Mute your phone and switch off your computer

Dinner
Time
7pm

Time for yoga !

- Remove your shoes (if you want)
- Get comfy
- Breathe
- Smile
- Enjoy !