

LET'S MAKE OPPORTUNITIES TO MEET AYAS CML MEMBERS!

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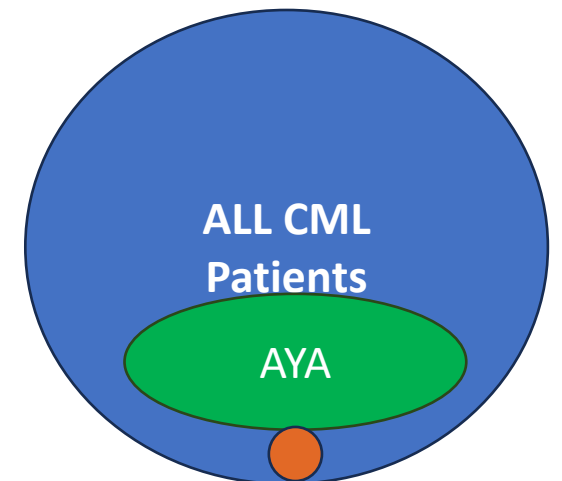
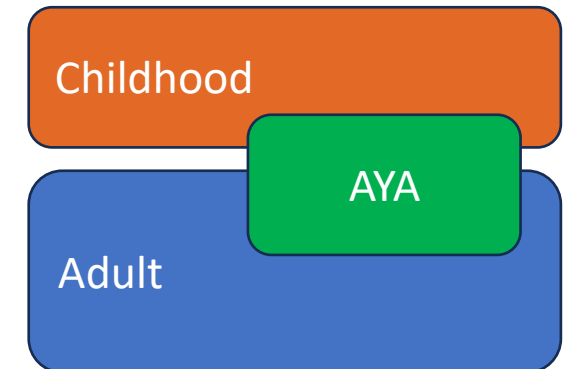
IZUMI The Association of CML patients & families
JAPAN

Advocacy Session #3
Best practice in patient advocacy
#CMLHZ23



Problem statement and background

- Are you aware what **AYA** means?
- Based on the National Cancer Institute definition, **AYA (Adolescent and Young Adult)** is an acronym that focuses on those diagnosed with cancer between the **ages of 15 and 39**. (Japan is the same.)
- **AYAs CML patients are very few** and scattered throughout the country.
- I was diagnosed with CML in 2005 at the age of 22.
- It took me a long time to meet my peers of my generation.



Implementation (I) Survey of AYAs CML

- A survey of patients, including AYAs, in Izumi was conducted in collaboration with Otsuka Pharmaceutical.(2023)
 - n=355(AYAs=43)
- **AYAs had more access to CML information than other generations** (especially on websites and SNS).
- **51% of AYAs** said they were having trouble with "**financial burdens** (e.g., medical expenses) which is higher than any other generation.
- Current state of mind, those **AYAs are less "positive" than other generations.**
 - Positive=51%, Feel down(sad)=33%



Implementation (II) Online Meeting

- I initiated efforts to connect AYA CML survivors in Japan.
- COVID-19 provided an opportunity for everyone to be able to conduct online meetings.
- **Two meetings** were held since 2022, **with 6 and 5 participants**.
- Our meetings included survivors in their 20s and 30s who had been diagnosed with CML, as well as survivors who had childhood cancer.



Implementation(III)

- They spoke of their troubles.



I suffer from thinning hair and always wear a hat.



I am taking TKI , so we must avoid pregnancy.

However, everyone was delighted to realize that their experiences were not unique to themselves, and **they were happy to have met fellow survivors.**



Result and Impact:

- *They need the opportunity to share their experiences;*
 - *One of the AYAs members was a speaker at the 922 event in 2023.*
 - *Fellow students who went on to art school wrote stories about her experiences and wonderful illustrations for IZUMI's publications.*
- *In addition to our regular online meetings, we plan to meet face-to-face.*





CML ADVOCACY - LEARN, SHARE, GROW
21TH INTERNATIONAL CONFERENCE FOR
ORGANISATIONS REPRESENTING PATIENTS
WITH CML



Conclusion and recommendation:

- AYAs CML survivors are few in every country,
 - and they likely share unique concerns specific to their generation.
 - and their concerns are often difficult to express to other generations.
- We encourage you all to provide opportunities for AYAs peers to make new friends as well.

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