



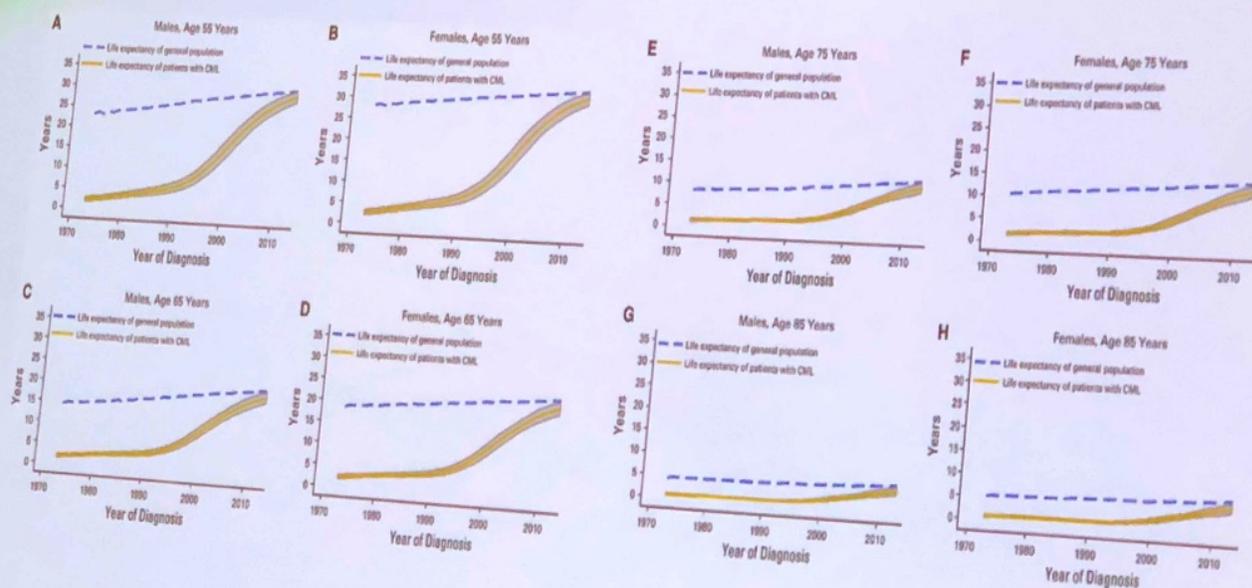
# CML Advocates Network

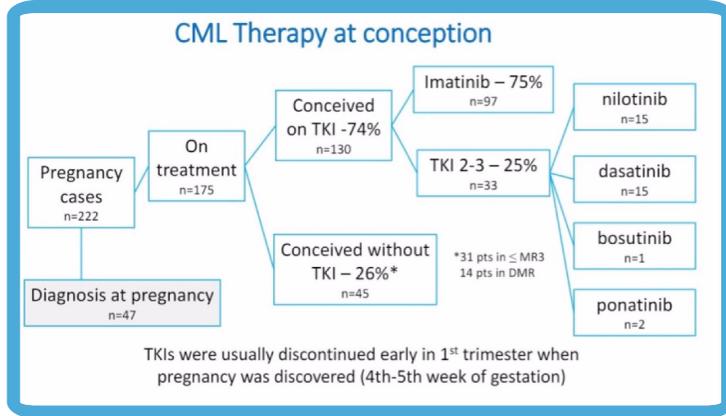
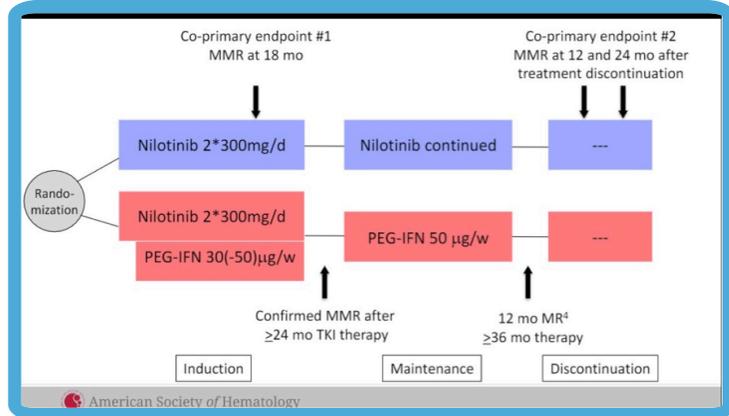
*For Chronic Myeloid Leukemia Patient Group Advocates*

**CML Advocates Network, ASH 2019**

## Life expectancy of patients with CML

Bower et al: JCO 2016





## 61st American Society of Hematology Congress Chronic Myeloid Leukemia reports

In December 2019, the [American Society of Hematology held its 61st Congress](#) in Orlando, USA.

The CML Advocates Network, with the help of our team of patient advocates, has summarized the chronic myeloid leukemia highlights presented in this key meeting for our community:

- Update on stopping CML treatment
- Discontinuation of TKIs in children with CML
- New drugs for CML, generic Imatinib and other topics
- CML Educational session

**Check and download the full #ASH19 CML AN Congress Report**

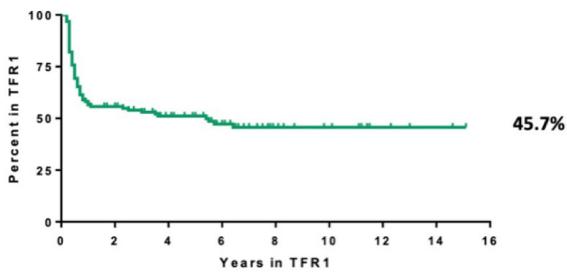
### Update on stopping CML treatment: Therapy-Free Remission

Achieving therapy-free remission (TFR) continues to be amongst the most discussed topics in CML at the moment. At this year's [ASH congress](#), the first plenary oral session on CML was dedicated to the topic of TFR and there were many posters as well.

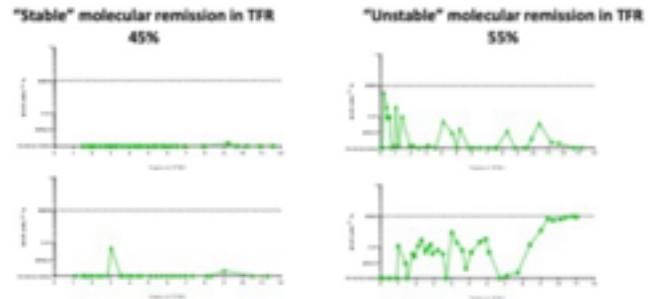
Overall, there is no big news in the area of TFR, but research continues

intensively. Across all the different studies, about half of all patients that are stopping therapy after years of deep molecular response to TKI (below MR4 / BCR-ABL below 0.01) need to restart treatment. The main open questions remain to predict the individual patients' likelihood of a successful stop, the need for life-long PCR monitoring to catch potential late recurrences of CML, and whether a second attempt to withdraw therapy is feasible and safe.

TFR1 : overall results  
Median follow-up in TFR1: 6.5 years



Two main patterns for long term (>2 years) TFR1



[Click here to read and download the full report](#)

## Discontinuation of TKIs in children with CML

TKIs seem to allow most CML patients, including children, to live a normal lifespan under continued treatment. However, the medication's long-term side effects such as growth impairment and the need to take the drug for the rest of life, are an issue of concern, especially for children.

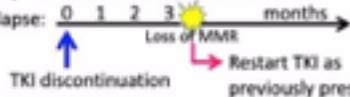
Recent clinical trials in adults have suggested that some CML patients in deep molecular response on TKI therapy may have a chance to discontinue TKI treatment. However, the biology of CML in children may differ from adults with a more aggressive presentation, and data of TKI discontinuation in CML children are limited.

## JPLSG STKI-14 study

- Multicenter prospective study
- Registration period: 2015/6/1 – 2016/12/31
- Follow up period: – 2018/12/31
- Inclusion criteria:
  - ✓ Diagnosed with CML-chronic or accelerated phase at <20 years of age
  - ✓ Treated with TKI for ≥3 years
  - ✓ Sustained molecular response (MR) 4.0 for ≥2 consecutive years

### Primary endpoint:

Treatment-free remission (TFR) rate at 12 months after TKI discontinuation

- Definition of molecular relapse: 

Restart TKI as previously prescribed

## Patients characteristics

	n (%), or median (IQR)
Age at diagnosis, years	9 (3 – 11)
Age at TKI discontinuation, years	16 (15 – 18)
Sex	Male 16 (72)/Female 6 (28)
Sokal score: low/intermediate/high	17/3/2 (77/14/9)
EUTOS score: low/high	18/4 (82/18)
Interferon alpha before TKI	2 (9)
Type of TKI	Imatinib only 19 (86) 2nd generation TKI +/- imatinib 3 (14)
Prior HSCT	3 (14)
Duration of TKI before TKI discontinuation, months	102 (63 – 136)
Duration of MR4.0 before TKI discontinuation, months	53.5 (40 – 78)
Time of TKI treatment before MR4.0, months	22 (15 – 36)

[Click here to read and download the full report](#)

## New drugs for CML, generic Imatinib and other topics

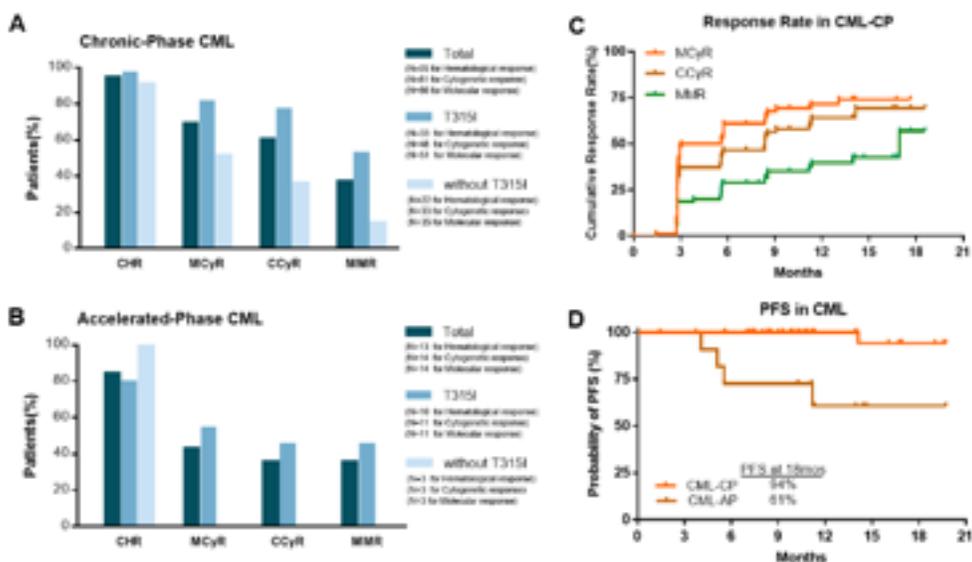
This summary will cover a few of the important topics regarding CML that were presented at ASH 2019 including:

- New Drugs for CML
- Update on the French and German Interferon combination studies
- Age-adjusted treatment in CML- Elderly and Pregnancy report for young CML patients. (our report regarding pediatric CML was published separately).
- Generic Imatinib

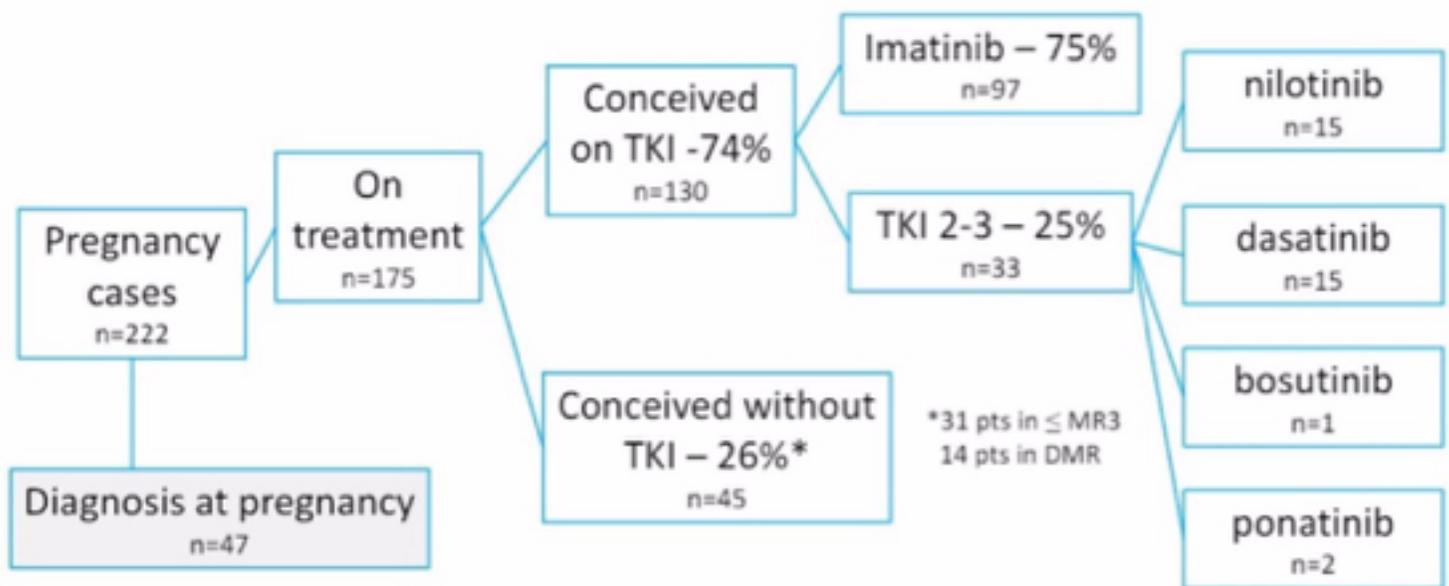
Table1. Treatment-Related Adverse Events

	Treated Population (N=101)		
	Any Grade	Grade 3/4	Serious
	number of patients (percent)		
<b>Non hematological AEs</b>			
Skin pigmentation	79 (78.2%)	0	0
Hyperglycaemia	55 (54.5%)	8 (7.9%)	0
AST elevation	37 (36.6%)	3 (3.0%)	0
Proteinuria	35 (34.7%)	5 (5.0%)	0
ALT elevation	34 (33.7%)	2 (2.0%)	0
Bilirubin elevation	34 (33.7%)	1 (1.0%)	0
Hypocalcaemia	34 (33.7%)	0	0
GGT elevation	24 (23.8%)	0	0
Hyponatremia	23 (22.8%)	0	0
Hyperglycaemia	21 (20.8%)	0	0
Myalgia	21 (20.8%)	0	0
CPK elevation	20 (19.8%)	2 (2.0%)	0
Hypokalaemia	20 (19.8%)	0	0
Pyrexia	18 (17.8%)	7 (6.9%)	1 (1.0%)
Rash	15 (14.9%)	2 (2.0%)	0
Skin rash	10 (9.9%)	1 (1.0%)	0
<b>Hematological AEs</b>			
Thrombocytopenia	76 (75.2%)	50 (49.5%)	6 (5.9%)
Anaemia	25 (24.8%)	12 (11.9%)	2 (2.0%)
Leukopenia	21 (20.8%)	20 (19.8%)	0

\*Cut-off date was 27May2019



## CML Therapy at conception



TKIs were usually discontinued early in 1<sup>st</sup> trimester when pregnancy was discovered (4th-5th week of gestation)

[Click here to read and download the full report](#)

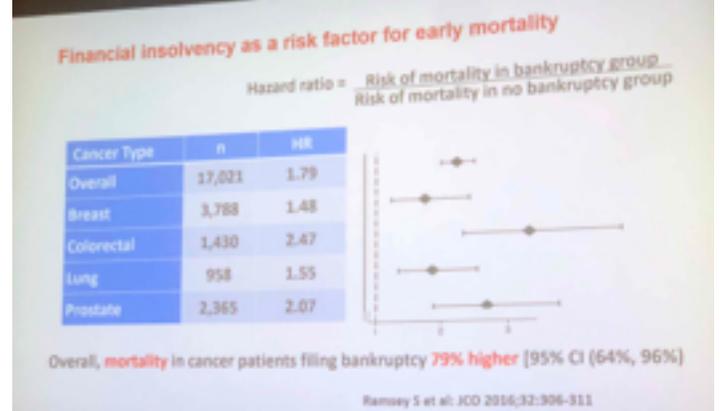
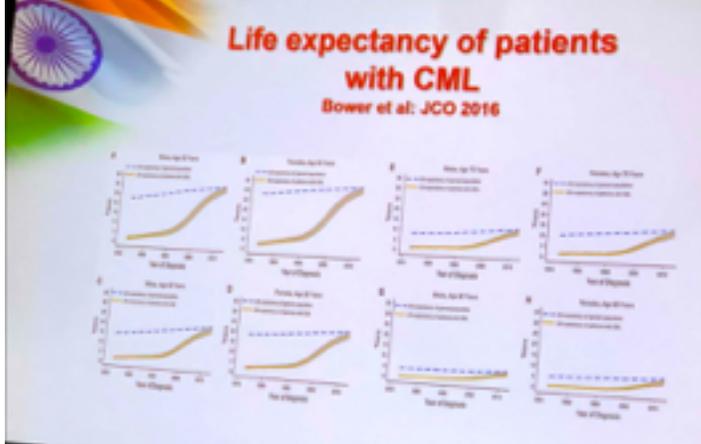
### CML educational session from ASH 2019

#### *Patients, borders, money, and mission: A global perspective of chronic myeloid leukemia*

CML is truly one of our cancer success stories. The identification of a single genetic swap — BCR-ABL — and the development of tyrosine kinase inhibitors (TKIs) targeting this mutation have revolutionized care for patients with the disease.

Globally, however, deep challenges remain.

Treatment challenges for CML in resource-poor countries, along with unique interventions that may help, were at the center of this enlightening session.



[Click here to read and download the full report](#)

**Play**

**Prof. Tim Hughes**  
Royal Adelaide Hospital, Adelaide, Australia

During the last American Society of Hematology Congress, we interviewed one of the key CML experts, Professor Tim Hughes, with the support of our colleagues of Leukaemia Care.

Thanks to all of you for your collaboration!

Don't miss the video on our Youtube channel summarizing the most important CML news presented at #ASH19

**CML**  
**HORIZONS** 2020



**SAN JOSÉ**  
**COSTA RICA**  
**1-3 MAY 2020**



**CML ADVOCACY -**  
**LEARN, SHARE, GROW**  
**18TH INTERNATIONAL**  
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**ORGANIZATIONS**  
**REPRESENTING PEOPLE**  
**WITH CML**

#CMLHZ20

**Are you planning to attend**  
**CML Horizons 2020?**

**Register here!**

Ask us how we can help  
facilitate your participation.

[lidija@cmladvocates.net](mailto:lidija@cmladvocates.net)



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[info@cmladvocates.net](mailto:info@cmladvocates.net)

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