

### CML ADVOCACY - LEARN, SHARE, GROW 20TH INTERNATIONAL CONFERENCE FOR ORGANISATIONS REPRESENTING PATIENTS WITH CML



### **CML HORIZONS HYBRID 2022**

## LEARN. SHARE. GROW. 28 - 30 OCTOBER 2022

Time Zone: Local Marrakesh time WEST same as London - Greenwich

### DAY 1: Friday 28th October 2022

10:00 - 10:45	CML 101 Jerry Clements
10:45 - 11:15	Opening: Šarūnas Narbutas & Rod Padua Welcome: Bahija Gouimi Minute of silence
11:15 - 11:45	Coffee Break
11:45 - 13:15	Advocacy #1 Best Practice Sharing Chairs: Rod Padua & Jana Pelouchová  1. DAR AL AMAL: Patient and Family Housing - Bahija Gouimi (15 min + 5 Q&A) 2. SEBAS: Solution and Evidence of Access Barriers in Health - Yolima Méndez (15 min + 5 Q&A) 3. Virtual Counselling Centre - Milica Kuzmanovska (15 min + 5 Q&A) 4. Ukraine Response - Cornelia Borowczak & Jelena Čugurović (15 min + 5 Q&A)
13:15 - 14:15	Lunch
14:15 - 15:45	<ul> <li>Medical #1 New Treatment Strategy</li> <li>Chairs: Lisa Machado &amp; Jerry Clements</li> <li>Specific inhibition of BCR: ABL1 first line - advantage for tolerability</li> <li>Speaker: Andreas Hochhaus (15 min + 10 min Q&amp;A)</li> <li>New Drugs &amp; Combination treatment</li> </ul>

Speaker: Jane Apperley (15 min + 10 min Q&A)

• Is asciminib a major step forward in the treatment of CML (debate 15 min each) Debate: **Yes:** Andreas Hochhaus and **No:** Jane Apperley – (Oxford style debate + 10 min Q & A)

#### Coffee Break 15:45 - 16:15 **Presentation of Steering Committee Nominees Denis Costello** 16:15 - 16:30 open Forum Questions if any to nominee & answer

Introduction to next session - Denis Costello

16:30 - 18:00 Advocacy #2 CML AN Projects market place each session will be 15 min incl Q&A and 3 min to change stations

- 1. CAB Update = Speaker: Jan Geissler
- 2. Know you CML App = Speaker: Šarūnas Narbutas
- 3. World CML Day = Speaker: Marija Stefkova
- 4. ELN Platform & New CML Website = Speaker: Denis Costello
- 5. CML Life Handover = Speaker: Jasmine Malone
- Dinner at Hotel 19:00



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### DAY 2: Saturday 29th October 2022

### 09:00 - 10:30 Medical #2 Treatment Free Remission (TFR)

Chair: Nigel Deekes & Eunice Orekha

• Latest Update on Attempting TFR for the second time

Speaker: Francois-Xavier Mahon (20 min + 10 min Q & A)

• TFR in LMICs: Is it really feasible?

Speaker: Pr Asmaa Quessar (20 min + 10 min Q & A)

Is TFR the Cure?

Debate: **Yes:** Giora Sharf or **No:** Jan Geissler (15 min each)

### 10:30 - 11:00 Coffee break

## 11:00 - 12:30 Advocacy #3 Regional session - strategic evaluations, memberships, and what the network can offer you?

- 1. Latin America
- 2. Western Europe
- 3. Asia and Pacific
- 4. Africa Middle East Asia
- 5. Eastern Europe
- 6. North America (room not needed)

### 12:30 - 12:40 Group Photo

12:40 - 13:45 Lunch

### 13:45 - 15:30 Medical #3 Challenges in CML

Chair: Šarūnas Narbutas & Bahija Gouimi

 Pregnancy & Fertility in CML while using TKIs & What's new with pregnancy and CML management

Speakers: Eunice Orekha patient story 10 min followed by Jane Apperley (20 min + 5 min Q&A)

Resistance - disease progression on TKIs

Speakers: Michal Paz Rosin patient story 10 min followed by Andreas Hochhaus (20 min + 5 min Q&A)

• Severe side effects while Living with TKI

Speakers: Bert Spangemacher – joining virtually patient story 10 min followed by – Francois-Xavier Mahon (20 min + 5 min Q&A)

### 15:30 - 16:00 Coffee break

18:45

### 16:00 - 17:30 Advocacy session #4 Access to treatment

Patient involvement in access decisions (Split into two groups)

### Room: Bahia - Group 1: Patients involved in access challenges with existing TKIs

Moderator: Pat Garcia-Gonzalez (15 min)

- Max Family Malaysia involvement in local Access Abd Razak Muhamad joining virtually (15 min)
- Iclusig access in Serbia -role of advocates Jelena Čugurović (15 min)
- Touched by Max Advocacy involvement of cutting through red tape Rod Padua (15 min)
- Open floor discussions (30 min)

Room: Koutoubia - Group 2: Patients formally involved in access decisions (e.g., HTA) - How can we advocate for access to new therapies?

Moderator: Zack Pemberton-Whiteley (20 mins + 5 Q&A)

• Best Practice in HTA process presentations from advocates

Speaker: Lisa Machado & Jana Pelouchová (10 minutes each + 10 Q&A)

· Panel discussion

Speaker: Zack Pemberton-Whiteley, Lisa Machado, Jana Pelouchová, Jane Apperley, Michaela Dinboeck (joining virtually) (25 min + 10 Q&A)



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### DAY 3: Sunday 30th October 2022

9:00 - 11:00 Advocacy #5 Evidence and data

Chairs: Zack Pemberton-Whiteley and Jan Geissler

Part 1: Examples of evidence-based advocacy; Why do we need Evidence Based Advocacy

Speaker: Zack Pemberton-Whiteley (15 min)

• Example 1: WECAN - Ananda Plate (15 min)

• Example 2: By the patient, for the patient

• Promoting Adherence Improving Compliance Asia & Pacific Region - Viji Venkatesh (15 min)

• Panel discussion:

Speaker: Zack Pemberton-Whiteley, Jan Geissler, Ananda Plate, Viji Venkatesh (15 min + 10 Q&A)

• Introduction and explanation to Part 2 by Zack Pemberton-Whiteley (5 min)

Part 2: Evidence-based advocacy task (Split into 3 groups)

Moderated by: Zack Pemberton-Whiteley, Jan Geissler and Lisa Machado (40 min)

11:00 - 11:30 Coffee break

11:30 - 12:30 Report from regional sessions and presentation of new SC members

Denis Costello (40 min)

Best poster award, closing and farewell

Giora Sharf (15 min)

12:30 - 13:30 Farewell Lunch

13:45 Meet in Lobby for Tour

14:00 Departure