

**Leukämie**  
online.de



## Online Seminar Series

# "Knowledge Horizons – current perspectives on living with CML"

Cornelia Borowczak

LeukaNET e.V., Deutsche CML-Allianz, CML Advocates Network

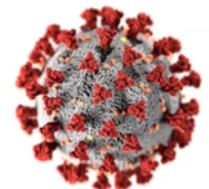
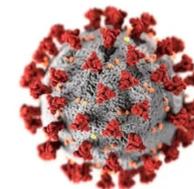
CML Horizon, October 22nd, 2021

# Leukämie online.de

- Launched approximately 20 years ago, “Leukämie Online” is a German-speaking online platform for leukaemia patients with a focus on CML .
- Meetings have been held since 2005 to bring the "onliners" together and to inform patients and their relatives.
- Over the years, there have always been about 120 participants at the F2F meetings.



- **But:** many cannot make the long journey to the meeting due to health issues, lack of time or costs.
- Due to the Corona pandemic, no more F2F meetings could take place.
- Personal contact was only possible by telephone, in written form or via video chat.
- **But:** patients want contact, help and exchange.



Leukämie  
online.de



## Cooperation of German stakeholders for CML patients

- **LeukaNet e.V.** is a registered patient organisation in Germany.
- with its online presence "Leukämie Online" LeukaNet e.V. provides detailed up-to-date information and a discussion forum for CML patients.
- **German CML Alliance** is an initiative for the improvement of CML management in Germany.
- CML practitioners from private practices, community and private clinics and university hospitals are working together with laboratory diagnosticians and patient advocates to expand and facilitate access to clinical trials.
- Together we developed the idea of providing a knowledge and learning tool for CML patients and their relatives.
- Our online seminar series "Knowledge Horizons – current perspectives on living with CML" was born.

## Why do these online seminars exist?

- *From a medical point of view:*
  - **Patient education** is an essential requirement for the success of treatment.
  - Well-informed patients are empowered to make informed **treatment decisions** together with their physicians.
  - Active and interested patients undertake an important role as **partners in clinical research** and bring in the patient's point of view.
  - New therapies developed on the road to recovery in this way can take **the needs of patients** into account.
- *From a patient point of view:*
  - Every patient has an **individual experience** on CML.
  - Being informed about treatment as well as exchange with other patients about the daily management of the disease **helps to deal with the disease**.
  - These online meetings give people with CML a chance to do just that.
  - Online services are particularly effective in **providing comprehensive information** and sharing experiences in times of the Corona pandemic.

## About CML online seminars

- The approx. 60-minute online seminars are livestreamed via Zoom (registration via <https://www.leukaemie-online.de/cml-onlineseminare>) and via Facebook livestream (no registration required).
- Questions can be asked via Q&A box and will be answered live after the lecture.
- all seminars are available on demand:
  - <https://www.leukaemie-online.de/cml-onlineseminare>, here can also be found answers to additionally asked questions
  - [https://www.uniklinikum-jena.de/cml/cml\\_allianz\\_mediathek\\_oeffentlich.html](https://www.uniklinikum-jena.de/cml/cml_allianz_mediathek_oeffentlich.html) (public access area to contents of the CML Alliance website)
- The online seminars are sorted by topic on the website:
  - CML treatment
  - Living with CML
  - CML in children and adolescents
  - CML in times of the Corona pandemic



## Online seminars - a useful tool?



- **More patients are reached** than with face-to-face events:
  - 37 – 560 participants (depending on topic)
  - Recordings can be played as often as desired
  - > **7.200** views via website (Vimeo), viewed more than **4,383** hours
  - > **106** hours of use via Facebook: 47.6 h live, 58.8 h afterwards
- Reduced time and costs for participants and speakers

**Leukämie**  
online.de



- launched on September 22, 2020, for World CML Day (“CML – Guidelines & Milestones”)



- 132 participants live via ZOOM
- 569 on demand



■ 2020:

**CML-Leitlinien  
und Therapie-Meilensteine**



Prof. Andreas Hochhaus  
22. September 2020

CML – Guidelines & Milestones  
132 / 569\*

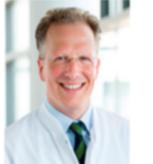
**Therapiefreie Remission  
(Absetzkonzepte in der CML-Therapie)**



Prof. Andreas Hochhaus  
26. Oktober 2020

TFR  
100 / 422\*

**CML in Zeiten von Corona**



Prof. Paul Graf La Rosée  
17. November 2020

CML in the times of Corona  
98 / 401\*

**CML bei Kindern &  
Jugendlichen**



Prof. Markus Metzler  
16. Dezember 2020

CML in Children & Adolescents  
37 / 84\*

\* Live / On Demand

■ 2021

**CML-Diagnostik**



Prof. Thomas Ernst  
19. Januar 2021

CML – Diagnostics  
105 / 218\*

**Generika bei CML**  
Situation in Deutschland und internationale Erfahrungen



Nicole Schröter  
15. Februar 2021

CML – Generics  
93 / 273\*

**Impfungen gegen COVID-19**  
bei Leukämien und MPN – was muss ich wissen?



Prof. Marie von Lilienfeld-Toal  
23. Februar 2021

Covid-19-vaccination in  
Leukemia & MPN  
560 / 1.457\*

**Impfungen gegen COVID-19**  
bei CLL, Lymphomen und Myelom – was muss ich wissen?



Prof. Marie von Lilienfeld-Toal  
3. März 2021

Covid-19-vaccination in CLL,  
Lymphoma & Myeloma  
308 / 2.710\*

**CML & Familienplanung**



Prof. Susanne Saußeke  
22. März 2021

CML & family planning  
51 / 138\*

**Klinische Studien in der CML**



Prof. Andreas Hochhaus  
12. April 2021

Clinical trials  
109 / 147\*

**Therapietreue**  
Ein unterschätztes Problem in der CML



Jan Geißler  
17. Mai 2021

Treatment adherence  
97 / 156\*

**Nebenwirkungsmanagement bei CML**



Prof. Dr. Alexander Kiani  
16. Juni 2021

Managing adverse events  
77 / 218\*

**Komplementärmedizin bei CML**



Prof. Dr. Jutta Hübner  
7. Juli 2021

Complementary medicine  
65 / 124\*

**TKI-Therapie bei Begleiterkrankungen**



Prof. Susanne Saußeke  
12. August 2021

TKI therapy for comorbidities  
48 / 98\*

**Schwerbehinderung bei pädiatrischer CML**



Prof. Dr. Meinolf Suttrop  
7. September 2021

Disability in paediatric CML  
28 / 26\*

**Leukämie**  
online.de



\* Live / On Demand

- planned

**Rehabilitation für  
Patient\*innen mit CML**



Dr. Andreas Willer   Dr. Thomas Stauch   Dr. Volker König

**19. Oktober 2021**

Rehabilitation for patients with CML  
October 19, 2021

**Zyto- und Molekulargenetik bei CML**  
Von der Blutprobe zum Befund



Prof. Dr. Alice Fabarius

**16. November 2021**

Cyto- and molecular genetics in CML -  
from blood sample to results  
November 16, 2021

**CML-Therapie**  
in der hämatologischen und  
onkologischen Schwerpunktpraxis



PD Dr. med. Thomas Illmer

**7. Dezember 2021**

CML therapy in haematological and  
oncological specialist treatment centres  
December 7, 2021

- "Knowledge Horizons – current perspectives on living with CML" were and will be moderated by:



**Jan Geißler**  
1. Chairman  
Leukaemie-Online / LeukaNET e.V



**Prof. Andreas Hochhaus**  
Chairman of the German CML-  
Alliance / University Hospital Jena



**Cornelia Borowczak**  
LeukaNET e.V. / Parents  
Organisation for Children with CML

**Leukämie**  
online.de



Many thanks to all of our seminar speakers!  
Thank you for the opportunity to present our  
project at the CML Horizon 2021!

and

Thank you for your attention!