



CLL HORIZONS 2021

Learn. Share. Grow.  **CLLAN**
CLL ADVOCATES NETWORK

CLL Horizons 2021: Learn. Share. Grow.
5 - 7 November 2021, virtual meeting

AGENDA

DAY 1: Friday 5 November 2021	
12:30–13:30 CET (60')	CLL 101: CLL Basics – <i>pre-recorded session – available on demand in advance to the formal opening of the meeting</i> Session Chairs: TBC (SC members)
13:30–14:00 CET (30')	Break
14:00–14:10 CET (10')	Opening – Welcome by the CLL Advocates Network – <i>live session</i> Speaker: TBC (SC member)
14:10–16:10 CET ('120)	Medical Session # 1 – Diagnosis, Active Surveillance (Watch and Wait) and Treatment Session Chairs: TBC (advocate and clinician)
14:10–14:15 CET (5')	<ul style="list-style-type: none"> Introduction to topic & speakers – <i>pre-recorded</i> Speaker: session chairs (see above)
14:15–14:30 CET (15')	<ul style="list-style-type: none"> The diversity of CLL – <i>pre-recorded</i> (The heterogeneity of CLL, i.e. variations of types of CLL and the influence of age, genetics, ethnics, gender, disease state, treatment, complications and comorbidities, etc.) Speaker: TBC (haematologist)
14:30–14:40 CET (10')	Session Break
14:40–14:55 CET (15')	<ul style="list-style-type: none"> Diagnosis and active surveillance – <i>pre-recorded</i> (Understanding the challenges and supporting the needs of those affected by CLL during diagnosis and "Watch and Wait") Speaker: TBC (haematologist)
14:55–15:10 CET (15')	<ul style="list-style-type: none"> First Line Treatment update – <i>pre-recorded</i> (Current CLL treatment and management guidelines, new developments and issues) Speaker: TBC (haematologist)
15:10–15:30 CET (20')	Q&A – <i>live session</i>
15:30–15:40 CET (10')	Session Break
15:40–16:10 CET (30')	Panel discussion: Managing emotional and psychological challenges of living with CLL – <i>interactive live session (audience attending by chat and other tools)</i> Panel: TBC (psychologists, supportive care / nurse, patients)
16:10–16:40 CET (30')	Break



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16:40–18:00 CET (80')	Advocacy Session # 1 – Evidence-based advocacy: Creating evidence for advocacy impact Chairs: TBC (advocates / CLLAN members)
16:40–16:45 CET (5')	<ul style="list-style-type: none"> Introduction to topic & speakers – <i>pre-recorded</i> Speaker: session chairs (see above)
16:45–17:00 CET (15')	<ul style="list-style-type: none"> Evidence-based advocacy – what’s behind the buzzword, and why is it important? – <i>pre-recorded</i> Speaker: TBC (expert members)
17:00–17:15 CET (15')	<ul style="list-style-type: none"> Understanding Evidence-Based Research Methods: Developing and Conducting Effective Surveys – <i>pre-recorded</i> <i>(Why do a survey? How to create survey questions? How to make good use of a survey? Examples.)</i> Speaker: Survey Service Provider
17:15–17:30 CET (15')	<ul style="list-style-type: none"> The results of CLLAN’s global CLL Resource Mapping and Unmet Needs Survey – <i>pre-recorded</i> Speakers: TBC (Survey Working Group)
17:30–17:40 CET (10')	Session Break
17:40–18:00 CET (20')	Q&A – <i>live session</i>
18:00–19:00 CET (60')	“The Pub” (<i>optional recreation event</i>) – <i>live networking session, quizzes, challenges</i>



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DAY 2: Saturday 6 November 2021 – “COVID-19 and CLL”

14:00–15:15 CET (75')	Shared session (Medical & Advocacy) # 1 – Management of the impact of COVID-19 on CLL patients Session Chairs: TBC (advocate and clinician)
14:00–14:05 CET (5')	<ul style="list-style-type: none"> Introduction to topic & speakers, structure of this shared session – <i>pre-recorded</i> Speaker: Session chairs (see above)
14:05–14:20 CET (15')	<ul style="list-style-type: none"> COVID-19 and CLL: the data – <i>pre-recorded</i> <i>(The global aspects of the pandemic and the impacts on CLL patients; clinical and patient group data)</i> Speaker: TBC (study group)
14:20–14:35 CET (15')	<ul style="list-style-type: none"> COVID-19 immunization: vaccines and other approaches for the immune compromised – <i>pre-recorded</i> <i>(Immunization response in CLL: How does this correlate to level of protection?)</i> Speaker: TBC (immunologist / haematologist)
14:35–14:45 CET (10')	Session Break
14:45–15:15 CET (30')	<p>Panel discussion: Living with an endemic pathogen - Supporting CLL patients to navigate safely in an evolving landscape – <i>interactive live session (audience attending by chat and other tools)</i> <i>(Discuss strategies, top tips and practical support)</i></p> <p>Panel: TBC (HCP, advocates/patients)</p> <p>Moderator: TBC (advocate)</p>
15:15–15:45 CET (30')	Break
15:45–16:35 CET (45')	Advocacy Session # 2 – Impact of the COVID-19 pandemic on patient advocacy and turning challenges into opportunities Chairs: TBC (advocates / CLLAN members)
15:45–15:50 CET (5')	<ul style="list-style-type: none"> Introduction to topic & speakers – <i>pre-recorded</i> Speaker: session chairs (see above)
15:50–16:05 CET (15')	<ul style="list-style-type: none"> Organisational Sustainability, good policy and process – <i>pre-recorded</i> <i>(Challenges that COVID-19 poses for advocates and patient advocacy organisations, advocates and self-care; evidence based upon results from survey)</i> Speakers: TBC (advocates)



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16:05–16:35 CET (30')	<p>Panel discussion: Choosing your advocacy priorities based upon evidence and resources – <i>interactive live session (audience attending by chat and other tools)</i> Panel: TBC (advocates/patients) Moderator: TBC (advocate)</p>
16:35–17:05 CET (30')	Break
17:05–17:10 CET (5')	<ul style="list-style-type: none"> Introduction, choice of best practice examples – <i>pre-recorded</i> Speaker: session chairs (see above)
17:10–17:40 CET (30') (10 minutes each)	<ul style="list-style-type: none"> “Hear from the regions”: The impact of the pandemic on Patient Organisations – <i>best practice examples of transforming challenges into opportunities</i> – <i>live session</i> <p><i>(The pandemic has severely impacted CLL support organisations and service delivery. Advocates are asked to submit an abstract ahead of the event to share best practice and their specific experience of service delivery during the pandemic. Three will be selected for workshop-style discussion.)</i></p> <p>Abstract presentation 1 (10 minutes) Abstract presentation 2 (10 minutes) Abstract presentation 3 (10 minutes)</p>
17:40–18:10 CET (30')	Q&A and discussion – <i>interactive live session (audience attending by chat and other tools)</i>
18:10–18:30 CET (20')	Best Poster Award Winners – <i>live session</i>
18:30–19:30 CET (60')	“The Pub” (<i>optional recreation event</i>) – <i>live networking session, quizzes, challenges</i>



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DAY 3: Sunday 7 November 2021

14:00–15:20 CET (80')	Medical Session # 2 – Ongoing Management of CLL Chairs: TBC (advocate and clinician)
14:00–14:05 CET (5')	<ul style="list-style-type: none"> Introduction to topic & speakers – <i>pre-recorded</i> Speaker: session chairs (see above)
14:05–14:20 CET (15')	<ul style="list-style-type: none"> Treatment update for relapsed and refractory CLL – <i>pre-recorded</i> (Current CLL treatment and management guidelines, new developments and issues) Speaker: TBC (haematologist)
14:20–14:35 CET (15')	<ul style="list-style-type: none"> Complications of CLL – <i>pre-recorded</i> (Complications such as immune complications, Richter’s transformation, infections, including comorbidities that may affect treatment) Speaker: TBC (haematologist / immunologist)
14:35–14:45 CET (10')	Session Break
14:45–15:00 CET (15')	<ul style="list-style-type: none"> Update on CLL Clinical Trials: What’s in the pipeline? New strategies? What is most promising? – <i>pre-recorded</i> Speaker: TBC (clinical researcher)
15:00–15:20 CET (20')	Q&A – <i>live session</i>
15:20–15:50 CET (30')	Break
15:50–17:10 CET (80')	Advocacy Session # 3 – Access to treatment, care and diagnostics – data-driven session based on patient experience surveys Chairs: TBC (advocates)
15:50–15:55 CET (5')	<ul style="list-style-type: none"> Introduction to topic & speakers – <i>pre-recorded</i> Speaker: Session chairs (see above)
15:55–16:25 CET (30')	<p>Panel discussion: Involvement of patients and advocates in new treatment appraisal processes (Health Technology Assessment) for access to new therapies – <i>interactive live session (audience attending by chat and other tools)</i></p> <p>Panel: TBC (HTA experienced advocates + advocate wishing to become involved in HTA processes) Moderator: TBC (advocate)</p>
16:25–16:35 CET (10')	Session Break
16:35–16:45 CET (10')	<ul style="list-style-type: none"> Recommendations and strategic insights from CLLAN’s 2021 survey results – <i>pre-recorded</i> Speaker: Session chairs (see above)



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16:45–17:15 CET (30')	<p>Panel discussion: Add your voice! Participative discussion to determine call to action to tackle unmet needs, barriers and historic & new challenges – <i>interactive live session (audience attending by chat and other tools)</i></p> <p><i>(Based on management report following CLLAN’s global needs survey to show differences across countries)</i></p> <p>Panel: TBC Moderator: TBC (advocate)</p>
17:15–17:30 CET (15')	Summary, observations and closing