



CLL HORIZONS 2019

LEARN • SHARE • GROW



INTERNATIONAL CONFERENCE FOR ORGANISATIONS REPRESENTING PEOPLE WITH CLL
EDINBURGH • SCOTLAND • 19-21 SEPTEMBER 2019

AGENDA





CLL Horizons 2019: AGENDA

19 – 21 September 2019

Novotel Edinburgh Centre, 80 Lauriston Place, Edinburgh, Scotland, EH3 9DE, UK

DAY 1: Thursday 19 September		Speakers	
Pre-Meeting - Foundation Learning Sessions			
10:30 – 12:00	<p>Option A: CLL 101</p> <p>1) CLL Basics:</p> <ul style="list-style-type: none"> Epidemiology Diagnosis, disease course, and staging Watch & wait Treatment & relapse <p>2) The changing therapeutic landscape</p> <p>3) Challenges to take to the conference – <i>discussion</i></p>	<p>Option B: Connecting Through Social Media</p> <p>1) How do we use social media to the best of our advantage?</p> <p>2) Developing and maintaining on-line support groups,</p> <p>3) How do we work with patient-run groups online (or do we)?</p> <p><i>3 x 20-minute talks each followed by group discussion</i></p>	<p>Option A</p> <p>Dr Brian Koffman (US) Michael Rynne (Ireland) Lorna Warwick (Canada)</p> <p>Option B</p> <p>Ciara O Donovan (Ireland) Jackie Martin (UK) Nick York (UK)</p>
12:00-13:15	Lunch		
13:15 -14:00	<p>Opening</p> <ul style="list-style-type: none"> Welcome & brief CLLAN update What to expect from the conference and how to make the most of your time Ice breaker 	<p>Nick York, Chair Lorna Warwick, Past Chair</p>	
14:00 -15:30	<p>Session #1 Living with a Diagnosis of CLL Workshop</p> <p>2 x 10-minute presentations</p> <p>Long term psycho-social and physical effects of a diagnosis of CLL: Challenges, living well and coping strategies.</p> <p>25-minute presentation and discussion</p> <p>Progress with ERIC/CERTH CLL Empowerment Programme: project update, materials, collaboration with CLLAN and advocacy community</p>	<p>Chair: Deborah Baker (Canada)</p> <p>Dr Brian Koffman (US) Kathryn Huntley (Australia) Dr Aliki Xochelli (Greece) Christina Karamanidou (Greece)</p>	



CLL HORIZONS 2019

LEARN • SHARE • GROW



INTERNATIONAL CONFERENCE FOR ORGANISATIONS REPRESENTING PEOPLE WITH CLL
EDINBURGH • SCOTLAND • 19-21 SEPTEMBER 2019

25-minute discussion groups	Group 1 - Explore opinions about the programme materials needed and next steps		
20 minutes	Group 2 - Explore opinions about how the programme may complement local support		
	Presentation of group discussion summaries to main plenary		
15:30 -16:00	Coffee break		
16:00 -17:30	Session #2 Concurrent Advocacy Workshops		
	<p>Option A: Barriers to Good Care (under a patient's control)</p> <p><i>10-minute presentation to frame discussion</i></p> <p><i>20-minute brainstorming: barriers patients' experience at all stages of the patient experience (i.e. finding a specialist, fear, information, cultural influence, adherence).</i></p> <p><i>Break out into 2 groups, each to discuss potential ways to support patients and remove barriers (40 min).</i></p> <p><i>Regroup and report back (20-minutes)</i></p>	<p>Option B: Organisational Sustainability</p> <p><i>2 x 15-minute presentations sharing new start up and established group experiences to frame discussion</i></p> <ul style="list-style-type: none"> - How do we keep our successful organisations functioning long-term? - Investigate succession planning & financial considerations <p><i>30-minute group discussion to identify and collect varied challenges & group discussion to identify and shortlist strategies CLLAN can adopt to support members and groups</i></p>	<p>Option A1</p> <p>Natacha Bolaños (Spain)</p> <p>Lelia Duley (UK)</p> <p>Michael Rynne (Ireland)</p> <p>Option A2</p> <p>Charlotte Martin (UK)</p> <p>Kathryn Huntley (Australia)</p> <p>Felice Bombaci (Italy)</p> <p>Option B</p> <p>Lorna Warwick (Canada)</p> <p>Jana Pelouchova (Czech Republic)</p> <p>Dr Neil Graham (New Zealand)</p> <p>Lise-Iott Eriksson (Sweden)</p>
19:00 - 23:00	Dinner at Hotel – Novotel Edinburgh		

Leukemia Patient Advocates Foundation (Stiftung Leukämiepatientenvertreter)

c/o Münzgraben 6, P.O.B. 453, CH-3000 Bern 7

Board: Jana Pelouchová • Jan Geißler • Giora Sharf • Erik Aerts

E-Mail: info@cmladvocates.net, Tel.: +49 (89) 62 836 807

Bank: IBAN CH020023523511353560M, SWIFT UBSWCHZH80A, UBS AG, Bärenplatz 8, CH-3000 Bern 94

Registration: Handelsregister des Kantons Bern – CH-036.7.052.001-2



CLL HORIZONS 2019

LEARN • SHARE • GROW



INTERNATIONAL CONFERENCE FOR ORGANISATIONS REPRESENTING PEOPLE WITH CLL
EDINBURGH • SCOTLAND • 19-21 SEPTEMBER 2019

DAY 2: Friday 20 September		Speakers
09:00 - 09:15	Recap of Day 1	Nick York
09:15 - 10:30	<p>Session #3 Testing Related to Treatment</p> <p>2 x 15-minute presentations & 15-minute discussion & debate</p> <p>2 x 10-minute presentations followed by 10-minute discussion</p> <p>1) Medical - Appropriate Testing: what, when and why</p> <ul style="list-style-type: none"> Standard of care and current state of the art What tests are needed to stratify patients to direct therapy for subgroups in a new treatment landscape? What has predictive prognostic value? As new therapies move into general front-line treatment, is testing still required? <p>2) Advocacy - Access to Tests</p> <ul style="list-style-type: none"> Patient perspectives on information and availability Identify issues and scope of problem 	<p>Chair: Brian Koffman (US)</p> <p>Dr Nicole Lamanna (US)</p> <p>Dr Kostas Stamatopoulos (Greece)</p> <p>Charlotte Martin (UK)</p> <p>Jennifer Wilson (US)</p>
10:30 - 11:15	Coffee Break with Poster Discussion	
11:15 - 12:15	<p>CLLAN – Moving Forward</p> <p>1) Report on current activities, membership, SC development</p> <p>2) Discuss potential activities to support advocate groups and SC expansion– what are the priorities?</p>	Current CLLAN Steering Committee
12:30 sharp	<i>Travel to shared afternoon sessions to join UK CLL Forum and clinical research community</i>	Meet in foyer to board coach
13:00 -14:00	Lunch at John McIntyre Conference Centre , University of Edinburgh Pollock Halls 18 Holyrood Park Road, Edinburgh EH16 5AY	
14:00 - 15:40	<p>Session #4 SHARED PLENARY</p> <p>UK CLL Forum & CLL Advocates Network (open to iwCLL participants)</p> <p>14:00 - 14:25 Optimal Therapy for CLL in 2019 – can we achieve this in the UK?</p> <p>14:25 - 14:50 CLL: What Do We Still Need to Learn? Current gaps in knowledge and care</p>	<p>Chairs:</p> <p>Dr Renata Walewska (UK)</p> <p>Nick York (UK)</p> <p>Prof Anna Schuh (UK) <i>University of Oxford</i></p> <p>Prof Chris Fegan (UK) <i>University Hospital of Wales</i></p>

Leukemia Patient Advocates Foundation (Stiftung Leukämiepatientenvertreter)

c/o Münzgraben 6, P.O.B. 453, CH-3000 Bern 7

Board: Jana Pelouchová • Jan Geißler • Giora Sharf • Erik Aerts

E-Mail: info@cmladvocates.net, Tel.: +49 (89) 62 836 807

Bank: IBAN CH020023523511353560M, SWIFT UBSWCHZH80A, UBS AG, Bärenplatz 8, CH-3000 Bern 94

Registration: Handelsregister des Kantons Bern – CH-036.7.052.001-2



CLL HORIZONS 2019

LEARN • SHARE • GROW



INTERNATIONAL CONFERENCE FOR ORGANISATIONS REPRESENTING PEOPLE WITH CLL
EDINBURGH • SCOTLAND • 19-21 SEPTEMBER 2019

14.50 - 15.15	International perspectives	Prof Paolo Ghia (Italy) <i>Università Vita-Salute San Raffaele</i>
15.15 - 15.40	Panel Discussion – Clinicians joined by advocates	
15.40 -16.00	Coffee break	
16.00 – 17.30	Session #5 Advocacy in Action <i>(subject to capacity open to UK CLL Forum & iwCLL participants)</i>	Chair: Dr Brian Koffman (US)
20-minute overview	1) Advocacy - Access to drugs: Patient Organisation Role & Perspective	<i>Speaker panel:</i> Lorna Warwick (Canada)
10-minute case study	<ul style="list-style-type: none"> Realistic ways POs can influence decisions, and where they can't Benefits of collaboration across communities. Examples of successful lobbying campaigns amongst patient organisations 	David Innes (UK) Zack Pemberton-Whiteley (UK) Pierre Aumont (France)
20-minute overview	2) Evidence Based Advocacy – Including the True Patient Voice	Deborah Baker (Canada)
2x10-minute case studies	<ul style="list-style-type: none"> Examples within international community of surveys and how they are used to influence planning & policy 	
20-minute Q&A		
19:00-23:00	iwCLL Reception @ Edinburgh Castle and Dinner at Novotel	

Leukemia Patient Advocates Foundation (Stiftung Leukämiepatientenvertreter)
c/o Münzgraben 6, P.O.B. 453, CH-3000 Bern 7

Board: Jana Pelouchová • Jan Geißler • Giora Sharf • Erik Aerts

E-Mail: info@cmladvocates.net, Tel.: +49 (89) 62 836 807

Bank: IBAN CH020023523511353560M, SWIFT UBSWCHZH80A, UBS AG, Bärenplatz 8, CH-3000 Bern 94

Registration: Handelsregister des Kantons Bern – CH-036.7.052.001-2



CLL HORIZONS 2019

LEARN • SHARE • GROW



INTERNATIONAL CONFERENCE FOR ORGANISATIONS REPRESENTING PEOPLE WITH CLL
EDINBURGH • SCOTLAND • 19-21 SEPTEMBER 2019

DAY 3: Saturday 21 September		Speakers
09:00 - 09:15	Recap of Day 2	Nick York
9:15 -10:30	<p>Session #6 Clinical Trial Strategies</p> <p>4 x 15-minute perspective presentations & 15-minute discussion</p> <p>1) Medical</p> <ul style="list-style-type: none"> Past strategies? Where are we in 2019? What's important to clinicians What's working and what's not - case studies Where are we going? <p>2) Advocacy</p> <ul style="list-style-type: none"> What's important to advocates? How can we work together to improve the system? 	<p>Chair:</p> <p>Michael Rynne (Ireland)</p> <p>Dr Alexey Danilov (US)</p> <p>Dr Adrian Bloor (UK)</p> <p>Natacha Bolaños (Spain)</p> <p>Lelia Duley (UK)</p>
10:30 -11:00	Coffee Break	
11:00 -12:00	<p>Session #7 Ongoing Complications of CLL</p> <p>3 x 15-minute presentations & 15-minute Q&A</p> <p>1) Medical</p> <ul style="list-style-type: none"> Managing an evolving condition – what are the complications? What does real world data tell us? <p>2) Advocacy</p> <ul style="list-style-type: none"> Personal experience: The good cancer is not so good 	<p>Chair:</p> <p>Jana Pelouchova (Czech Republic)</p> <p>Dr Nicole Lamanna (US)</p> <p>Dr Francesco Forconi (UK)</p> <p>Brian Gardom (UK)</p>
12:00 -12:20	<p>Plans Moving Forward</p> <p>Wrap up discussions in small groups with feedback re: what is one thing each delegate is taking back to implement?</p>	<p>Chair:</p> <p>Jana Pelouchova (Czech Republic)</p>
12:20 -12:30	Tribute to Chris Dwyer	Deborah Baker (Canada)
12:30 -13:00	Best Poster, Closing Session and Farewell	
13:00 -14:00	Farewell Lunch	
14:00 -15:00	Debrief with the sponsors	

As of 16th August 2019 – subject to change

Leukemia Patient Advocates Foundation (Stiftung Leukämiepatientenvertreter)

c/o Münzgraben 6, P.O.B. 453, CH-3000 Bern 7

Board: Jana Pelouchová • Jan Geißler • Giora Sharf • Erik Aerts

E-Mail: info@cmladvocates.net, Tel.: +49 (89) 62 836 807

Bank: IBAN CH020023523511353560M, SWIFT UBSWCHZH80A, UBS AG, Bärenplatz 8, CH-3000 Bern 94

Registration: Handelsregister des Kantons Bern – CH-036.7.052.001-2



CLL HORIZONS 2019

LEARN • SHARE • GROW



INTERNATIONAL CONFERENCE FOR ORGANISATIONS REPRESENTING PEOPLE WITH CLL
EDINBURGH • SCOTLAND • 19-21 SEPTEMBER 2019

Sponsorship Acknowledgement

We would like to thank the following sponsors for providing unconditional educational funding. Without their support the conference would not be possible.

Gold Sponsor

abbvie

Silver Sponsors



Bronze Sponsors



Leukemia Patient Advocates Foundation (Stiftung Leukämiepatientenvertreter)
c/o Münzgraben 6, P.O.B. 453, CH-3000 Bern 7

Board: Jana Pelouchová • Jan Geißler • Giora Sharf • Erik Aerts

E-Mail: info@cmladvocates.net, Tel.: +49 (89) 62 836 807

Bank: IBAN CH020023523511353560M, SWIFT UBSWCHZH80A, UBS AG, Bärenplatz 8, CH-3000 Bern 94

Registration: Handelsregister des Kantons Bern – CH-036.7.052.001-2