

SmartStart – Programme (Status: 8th of July 2015)



ARRIVAL THURSDAY, 9th July 2015

	Arrival and Registration	
19:00	INFORMAL GET-TOGETHER & WELCOME Foyer Meeting Area	Participants and available members of the faculty

DAY 1 FRIDAY, 10th July 2015 MODULE 1 From The Foundations Up - Building A National Non-Profit Patient Group

09:00 – 10:00 60 Min.	S01 Setting the scene / introduction: why are we here? “Patient power and patient centricity”? Success stories: see what’s achievable! The world of patient support and patient advocacy: It’s all about changing things – for individual patients – for many patients! What to do and how to do it? Understanding your role within the system/environment and defining target groups	Markus Wartenberg (DE) Short Success Story „Kidney Cancer Canada“ by Deb Maskens (CDN)
10:00 – 10:30	COFFEE BREAK	
10:30 – 12:00 90 Min.	S02 Fundamentals first: the strategic planning process – in theory and practice: mission, vision, values, SWOT analysis, strategic goals, actions, etc.	Markus Wartenberg (DE)
12:00 – 13:00	LUNCH BREAK	
13:00 – 13:45 45 Min.	S03 Some legal, organizational and management aspects: legal entity, important/useful documents, governance, internal communications, liability, insurance, risk management, leadership, sustainability, etc.	Erik Briers (BEL)
13:45 – 14:30 45 Min.	S04 Financial aspects: funding sources, charitable status, budgeting, accounting and record-keeping	Erik Briers (BEL)
14:30 – 15:15 45 Min.	S05 Financial aspects: How to do grant writing / funding requests	Deb Maskens (CDN) Markus Wartenberg (DE)
15:15 – 15:45	COFFEE BREAK	
15:45 – 17:15 90 Min.	S06 Branding and marketing your organisation: your brand, your identity vs your image, group’s name, logo, slogan, corporate design, behaviour, culture, communications, etc.	Herbert Thum (Designer, DE) Supported by Markus Wartenberg (DE)
17:15 – 18:15 60 Min.	S07 Starting a patient group - ask the Patient Expert Panel: an interactive discussion, open questions, sharing experiences	Patient Advocacy Organisations
19:30	Internal Course Dinner – Hotel Restaurant	

DAY 2 SATURDAY, 11th July 2015
MODULE 2 The Cancer World, Relationships And Working Within The System

08:30 – 09:15 45 Min.	S08	The era of targeted therapies, personalised medicine and immuno-oncology (a short overview of how we are treating cancer today)	Bettina Ryll (SWE)
09:15 – 10:00 45 Min.	S09	A basic introduction to clinical trials – Part 1 The ethical and organisational framework of clinical trials – Phases 1 - 4	Markus Wartenberg (DE)
10:00 – 10:30	COFFEE BREAK		
10:30 – 11:15 45 Min.	S10	A basic introduction to clinical trials – Part 2 The practical issues of patients in clinical trials and the role of patient groups	Bettina Ryll (SWE)
11:15 – 12:00 45 Min.	S11	Assessing promising treatments: approved treatments, off label use, programmes - such as early access / compassionate use, clinical trials	Bettina Ryll (SWE)
12:00 – 13:00	LUNCH BREAK		
13:00 – 13:45 45 Min.	S12	How to work with: volunteers, staff and/or freelancers	Deb Maskens (CDN)
13:45 – 14:30 45 Min.	S13	How to work with: physicians / key opinion leaders (KOLs)/ experts / researchers	Estelle Lecointe (FR)
14:30 – 15:15 45 Min.	S14	How to work with: the healthcare industry	Deb Maskens (CDN)
15:15 – 15:45	COFFEE BREAK		
15:45 – 16:30 45 Min.	S15	How to work with: the media	Kathy Oliver (UK) <i>(Remote presentation from Paris)</i>
16:30 – 17:15 45 Min.	S16	Role of other stakeholders – depending on your healthcare system: Understanding the basics of HTA/Reimbursement Decisions	Markus Wartenberg (DE)
17:15 – 18:45 90 Min.	S17	Role of patient advocacy and working within the healthcare system sharing best practice in patient advocacy – case studies/examples	Estelle Lecointe (FR) Deb Maskens (CDN) Jan Geissler (DE)
19:10 19:30	Transfer External Course Dinner – Brewhouse: Alt Oberurseler Brauhaus – Ackergasse 13 – 61440 Oberursel – Phone +49 6171 54370 http://meinbier.de/meinbier/brauhaus-international.html		

DAY 3 SUNDAY, 12th July 2015 (DAY OF DEPARTURE)
MODULE 3 Best Practices And Personal Skills for Patient Advocates

08:00 – 08:45 45 Min.	S18 Peer to peer support: hotline – online – face to face	Deb Maskens (CDN)
08:45 – 09:30 45 Min.	S19 Information and exchange – events/patient meetings strategic, organisational and practical issues	Markus Wartenberg (DE)
09:30 – 10:00	COFFEE BREAK (30 Min.)	
10:00 – 11:30 90 Min.	S20 Information and exchange – online tools and & social media tactics (website, newsletter, forum, mailing-lists, Facebook, Twitter, blogs, videos, etc.)	Jan Geissler (DE)
11:30 – 12:15 45 Min.	S21 Information - printed materials concept, content, writing, design, production, standards, impact	Markus Wartenberg (DE) Herbert Thum (Designer, DE)
12:15 – 13:00	SHORT LUNCH BREAK (45 Min.)	
13:00 – 13:45 45 Min.	S22 Information: making medical content understandable - communicating medical content such as studies and study results - collecting information / building evidence: registries, surveys, case studies, etc.	Jan Geissler (DE)
13:45 – 14:30 45 Min.	S23 Presentation and moderation skills for patient group leaders	Kathy Oliver (UK) <i>(Remote presentation from Paris)</i>
14:30 – 15:15 45 Min.	S24 Starting a patient group - ask the Patient Expert Panel: Final open questions – personal feedback... Granting of the Course Certificate	Faculty Members
15:00	END OF THE COURSE / EVALUATION FORMS / FAREWELL	