



A unique, three-day patient advocates' educational course

2015
July
9th – 12th
In Frankfurt

Starting And Building A National Non-Profit Patient Group.



A Collaborative Training Approach - supported by International Cancer Patient Networks, such as CML-Advocates, ELPA, Europa Uomo, IBTA, IKCC, MPNE, SPAEN ...

Supported by
Educational Grants from:
Initial Sponsor: Bayer HealthCare
Co-Sponsor:



TRAINING COURSE

“Starting and Building a National Non-Profit Patient Group.”

- Concept:** SmartStart is a unique, three-day patient advocates' educational course during which those who are relatively new to patient support and advocacy will have the opportunity to learn basic knowledge and tools which will provide the solid foundations for them to create and maintain a national not-for-profit advocacy/support organisation in their own country.
- Offer:** This training course provides
- the right knowledge to set up a national cancer patient advocacy and/or support group in Europe
 - experienced patient group leaders and other knowledgeable trainers who will share their experiences and best practices with the participants
 - a time-tested, balanced mix of practical advocacy and support “tools” for patient advocates.
- Important:** The course will not overwhelm participants with advocacy issues such as access, HTA, regulatory procedures, lobbying or advanced research knowledge, etc.
- Language:** Conference language will be in English.
Please do not be afraid to get involved in the conference even if you have limited English skills. **(Note: Translation will not be available)**
- Candidates:** Cancer Patient Advocates
- who are in the process of starting a group/organization,
 - who have already started a group/organization and are seeking to improve their skills as advocates,
 - who are relatively new in existing groups/organisations and who would like to take future responsibility as Chair, Board Member or Director.
- Criteria:** Candidates
- need to complete an application form (>>> Expression on Interest)
 - must fulfil the status of a volunteer, if they want to participate **for free**
 - should be affiliated with their groups/organisations to an international cancer patient advocacy network – such as CML Advocates Network, ELPA, Europa Uomo, IBTA, IKCC, MPNE, SPAEN or others...
- (Note: Paid staff of groups / organizations can participate for an affordable fee.)
- Status:** Pilot-Course. Depending on the feedback of the participants and the faculty members our intention is to run an annual course for prospective cancer patient advocates in Europe and countries outside Europe. Further course availability - will depend on available funding.
- Available Places:** Max 25 participants + 10 faculty members



- Training Days:** **Thursday 9th July 2016**
19:00 Informal get-together at the course hotel
- Friday 10th July 2015**
09:00 – 18:15 1st Day – 1st Module
19:30 Course dinner at the hotel
- Saturday 11th July 2015**
08:30 – 18:45 2nd Day – 2nd Module
19:30 Bus transfer and course dinner at external location
- Saturday 12^h July 2015**
08:00 – 15:30 3rd Day – 3rd Module and Departure
- Programme:** Please see Conference Programme. Modules:
1) From The Foundations Up - Building A National Non-Profit Patient Group
2) The Cancer World - Relationships And Working Within The System
3) Best Practices And Personal Skills for Patient Advocates
- Course Directors:** Markus Wartenberg – SPAEN – Germany
Kathy Oliver – IBTA – United Kingdom
- Faculty Members:**
- | | |
|---|-------------------|
| Erik Briers (BEL) – Europa Uomo | (Prostate Cancer) |
| Jan Geissler (DE) – CML Advocates Network | (Leukaemia) |
| Achim Kautz (DE) – ELPA | (Liver Cancer) |
| Estelle Lecointe (FR) – SPAEN | (Sarcoma/GIST) |
| Deb Maskens (CDN) – IKCC | (Kidney Cancer) |
| Kathy Oliver (UK) – IBTA | (Brain Tumours) |
| Bettina Ryll (SWE) – MPNE | (Melanoma) |
| Herbert Thum (DE) – VISKON | Graphic Designer |
| Markus Wartenberg (DE) – SPAEN | (Sarcoma/GIST) |
- Training Fee:** Invited participants attend this training course for free. Included at no cost to participants are: hotel room for three nights on a bed and breakfast basis, lunches on the days of the course, two course dinners and all conferences materials.
- Travel Grants:** Travel grants are available: Travel expenses are paid by the participants and can be reimbursed up to a maximum of 350 Euros per attendee. More details under: Reimbursement Rules
- Expression:
of Interest:** **Online-Process! Please go to:**
<http://daslebenshaus.org/index.php/veranstaltungen/smartstart-2015-application>
Here you will find an online application form. Please complete this form and submit your expression of interest. The Course Directors will evaluate your application and will send you feedback very soon after your request. The application process ends either when all 25 places are filled or **not later than June 7, 2015.**
If you have any questions, please do not hesitate to contact:
SmartStart2015@daswissenshaus.de

TRAINING LOGISTICS

Travel Information: By air:
Frankfurt/Main International Airport (FRA)

Not recommended: Airport Frankfurt-Hahn (HHN):
Approximately 120 KM from the venue/hotel!

By train:

1. Frankfurt Airport Railway Station
Destination for many ICEs (InterCity Express) and international trains
(approximately 1 KM from the venue/hotel)
2. Frankfurt Main Station – in Frankfurt downtown
(approximately 11 Km from the venue/hotel)

By car:

The hotel is located close to the main highway junction “Frankfurter Kreuz”.
Main German motorways A 3, A 67 and A 5 lead straight to Frankfurt Airport.
Currently Germany only collects tolls for trucks.
The venue/hotel offers underground parking for more than 100 cars.
An electric charging station is available.

Shuttle Service:

Easily transfer to and from Frankfurt Airport (including Frankfurt Airport Railway Station) via the hotel shuttle. Our hotel provides a daily Frankfurt Airport shuttle between the hotel, Terminal 1 and Terminal 2 every half hour from 05:00 to midnight. The shuttle stops at Terminal 1 (arrival level, area C, exit no. 8)



and at Terminal 2E (regular shuttle stop) and picks up guests free of charge. On the return trip to the airport there is a fee of EUR 4 per person. The hotel advises guests to book a seat at the reception desk in advance. The last pick-up from the airport is at 23:45 outside of Terminal 2E. The last shuttle in the evening leaves the hotel at 22:30 and returns to the hotel at 23:40 from Terminal 1 and at 23:45 from Terminal 2.

Venue/Hotel:

More information under: <http://www.parkinn.com/airporthotel-frankfurt>

Park Inn by Radisson Frankfurt Airport Hotel
Amelia-Mary-Earhart-Str. 10 - Gateway Gardens
60549 Frankfurt/Main - Germany
Phone: +49 69 900276-0
Email: info.frankfurt@rezidorparkinn.com

The Park Inn by Radisson Frankfurt Airport Hotel is a good accommodation choice with its proximity to the terminals and its array of excellent amenities including WiFi. The hotel has:

- a total of 209 guest rooms with flat-screen LCD televisions, individual climate control and WiFi
- the RBG Bar & Grill, which features a breakfast buffet and group catering menus
- a state-of-the-art fitness centre on the first floor

WiFi Access: Will be provided in your rooms – complimentary for faculty members and participants

Electricity: In Germany the standard voltage is 230 V.
The standard frequency is 50 Hz.
The power sockets that are used are of type F.



Time Zone: July = Summer Time (MESZ) or

Currency: The valid currency in Germany is EURO and CENT

Frankfurt Attractions: Cathedral of Emperors (Kaiserdom), Paulskirche
Römerberg (Roman Mountain)
Alte Oper – Old Opera
Museums: Städel, Senckenberg, Jewish Museum
Palmengarten and Frankfurter Zoo
Main River – Eiserner Steg (Ron Bridge or Lovers Bridge)
Banking Area – Skyscrapers (incl. EZB-Building)
Bull & Bear: Frankfurt Stock Exchange
Shopping: Zeil and Goethestrasse
Alt Sachenshausen – Apple-Wine-Restaurants

Distances: Hotel/Venue = 800 m from Frankfurt Intl. Airport – Terminal 2
10 min. drive to Commerzbank Arena
Frankfurt fair and downtown 12 km

Meeting Room: Main training room =
Gebrüder Wright = Wright Brothers

Contact: Your contact during the training will be Markus Wartenberg:
Phone: + 49 170 7914989
Email: SmartStart2015@daswissenshaus.de



Reimbursement & Funding

Reimbursement Rules

Invited participants attend this training course for free. Costs for accommodation and all training expenses will be directly paid to the hotel by the course organizers. SmartStart will also provide snacks, meals, beverages, including internal/external dinners for the days of the training.

Travel Grants: Travel expenses need to be paid by the participants and can be reimbursed up to a maximum 350 Euros per attendee.

PLEASE NOTE:

During the training course Expense Reimbursement Forms will be available. Please use these forms to reclaim your costs within 30 days of the end of the course. We regret we cannot reimburse expenses without an original receipt or after 30 days from the end of the course.

Other expenses: All other expenses (e.g. upgrade of rooms, difference from a single to double room, mini bar, hotel bar, additional meal orders, room service, telephone, laundry, etc.) will not be covered by SmartStart. Additional expenses incurred for accompanying persons cannot be covered by the organizers. All additional expenses incurred by course participants must be settled by them with the hotel at check out.

Funding Information

At the request of the organizers, this course has received grants from Bayer HealthCare Global. All sponsorships will be made transparent.

PLEASE NOTE:

These grants will have no relationship whatsoever with any of the objectives or content of the course. The idea, conception, planning, preparation, realisation, management and the summary of the course will be the responsibility of the organizers and the faculty members without any influence from the Sponsors.

The course is independently run and is not connected in any way whatsoever with pharmaceutical representatives in each country. Please do not contact your local country pharmaceutical representatives for assistance or additional funding. The course is delivered by a range of international patient advocacy networks such as CML Advocates Network, ELPA, Europa Uomo, IBTA, IKCC, MPNE, SPAEN which are independent networks of patient organisations without commercial influence.



Liability Disclaimer

Your participation in the “1st Smart Start Training Course” - taking place at Park Inn Hotel Frankfurt/Main Airport from 9th July to 12th July 2015 - will be solely at your own risk. This includes travelling to and from the training course.

- SmartStart - Das Wissenshaus GmbH (incl. international cancer patient advocacy networks, faculty members and funders) does not accept any liability for any loss or damage resulting from your participation in the course. Nor does it accept any liability whatsoever for any accident or injury or illness you may suffer, or your death, save if and in so far as directly caused by the negligence of SmartStart – Das Wissenshaus GmbH.
- The presentations, workshops and other sessions at the training course are for educational purposes only and are in no way intended to replace professional medical care, advice, diagnosis or treatment from a doctor, specialist or other healthcare professional.
- Company sponsorship of this training course does not imply our endorsement of any particular form or forms of therapy, devices, medical regimens, plans or behaviour referred to, promoted, manufactured, or distributed by those companies.
- The views expressed by those participating in the training course and providing presentations or workshop facilitation are not necessarily the views of Das Wissenshaus GmbH.
- The course programme was carefully prepared and carried out on the basis of current knowledge of the topics concerned however, SmartStart – Das Wissenshaus GmbH accepts no liability for the accuracy or currency of the information presented during the training.
- Herewith all participants have been notified by Smart Start – Das Wissenshaus GmbH to obtain adequate travel insurance/health cover for the entire period of their stay in Germany. The organizers accept no liability whatsoever for any medical treatment/emergencies or care required by any of its participants during the period of the course. SmartStart – Das Wissenshaus GmbH will not reimburse expenditure incurred by participants requiring any medical care in the event that a Summit participant has no medical insurance coverage or insufficient medical insurance coverage to pay for any treatment or hospitalisation.

SmartStart – Programme (Status: 27th March 2015)

ARRIVAL THURSDAY, 9th July 2015

	Arrival and Registration	
19:00	INFORMAL GET-TOGETHER & WELCOME	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	Kathy Oliver (UK) Markus Wartenberg (DE)
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	Markus Wartenberg (DE) Deb Maskens (CDN)
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.	Markus Wartenberg (DE) Herbert Thum (Designer, 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	Achim Kautz (DE) 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	Accessing 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)
16:30 – 17:15 45 Min.	S16	Role of other stakeholders – depending on your healthcare system: insurance companies, payers, HTA bodies, etc.	Achim Kautz (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)
19:30 20:00	Bus-Transfer External Course Dinner (incl. Granting of the Course Certificate)		

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	The basics of project management	N.N.
14:30 – 15:15 45 Min.	S24	Presentation and & moderation skills for patient group leaders	Kathy Oliver (UK)
15:15 15 Min.	END OF THE COURSE / EVALUATION FORMS / FAREWELL		