



Application Form EURORDIS Summer School

Barcelona, June 2 - 6, 2014

Training Rare Disease Patient Advocates
in Clinical Trials and Drug Development

(Please complete all sections: only completely filled forms will be considered)

1. Your contact details			
First name		Last name	
E-mail		Telephone	
Address		Postal code	
City		Country	
2. Contact details in case of emergency			
First name		Last name	
Telephone		Mobile phone	
Address		Postal code	
City		Country	
3. Your organisation			
Name:			
Disease(s) represented:			
Type of organisation (please tick only one):			
<input type="checkbox"/> Governmental <input type="checkbox"/> Non-governmental/not-for-profit <input type="checkbox"/> Educational/research institution <input type="checkbox"/> Transnational/Intergovernmental <input type="checkbox"/> Informal <input type="checkbox"/> Other (please specify):			
E-mail		Website	
Telephone		Fax	
Address		Postal code	
City		Country	
4. Your role in the patient organisation			
Are you? Please tick ✓ all that apply	Patient		Staff
	Family of patient		Volunteer
How long have you been active in the organisation? What are your roles or activities? (10 lines max)			

Do you represent your organisation in any European Committee/Task Force/ Working Group? If yes, please specify	
What is your professional background? (10 lines max.)	

5. English language skills

	Reading	Writing	Speaking	Overall
Please rate your English language skills	<input type="checkbox"/> Native/Advanced <input type="checkbox"/> Good <input type="checkbox"/> Intermediate <input type="checkbox"/> Basic <input type="checkbox"/> None	<input type="checkbox"/> Native/Advanced <input type="checkbox"/> Good <input type="checkbox"/> Intermediate <input type="checkbox"/> Basic <input type="checkbox"/> None	<input type="checkbox"/> Native/Advanced <input type="checkbox"/> Good <input type="checkbox"/> Intermediate <input type="checkbox"/> Basic <input type="checkbox"/> None	<input type="checkbox"/> Native/Advanced <input type="checkbox"/> Good <input type="checkbox"/> Intermediate <input type="checkbox"/> Basic <input type="checkbox"/> None

6. Your experience/knowledge (5 lines max.)

Please describe any past and current involvement in clinical trials and drug development:

7. Drug Development (10 lines max.)

Please describe your past or potential drug development collaborations with research groups, pharmaceutical companies or actions for the development of drugs in your disease.

8. Expectations (10 lines max.)

Please describe your expectations related to this summer school and how you think this training will help you in your activities.

9. Please describe your experience in:

Design and objectives of clinical trials and the roles of all stakeholder	Patients' roles & responsibilities in innovative medicines development	Interaction with stakeholders (regulators, industry, etc.) in drug development processes
<input type="checkbox"/> Advanced (5+ years of experience) <input type="checkbox"/> Good (3-5 years of experience) <input type="checkbox"/> Intermediate (1-3 years of experience) <input type="checkbox"/> Basic (under 1 year of experience) <input type="checkbox"/> None	<input type="checkbox"/> Advanced (5+ years of experience) <input type="checkbox"/> Good (3-5 years of experience) <input type="checkbox"/> Intermediate (1-3 years of experience) <input type="checkbox"/> Basic (under 1 year of experience) <input type="checkbox"/> None	<input type="checkbox"/> Advanced (5+ years of experience) <input type="checkbox"/> Good (3-5 years of experience) <input type="checkbox"/> Intermediate (1-3 years of experience) <input type="checkbox"/> Basic (under 1 year of experience) <input type="checkbox"/> None
Medicines development process from pre-clinical research to approval	Drug safety and risk/benefit assessment of medicines	Pharmaco-economics, health economics and health technology assessment
<input type="checkbox"/> Advanced (5+ years of experience) <input type="checkbox"/> Good (3-5 of years of experience) <input type="checkbox"/> Intermediate (1-3 years of experience) <input type="checkbox"/> Basic (under 1 year of experience) <input type="checkbox"/> None	<input type="checkbox"/> Advanced (5+ years of experience) <input type="checkbox"/> Good (3-5 of years of experience) <input type="checkbox"/> Intermediate (1-3 years of experience) <input type="checkbox"/> Basic (under 1 year of experience) <input type="checkbox"/> None	<input type="checkbox"/> Advanced (5+ years of experience) <input type="checkbox"/> Good (3-5 years of experience) <input type="checkbox"/> Intermediate (1-3 years of experience) <input type="checkbox"/> Basic (under 1 year of experience) <input type="checkbox"/> None

10. Commitment

Please evaluate your level of commitment to potentially be involved in clinical trial and drug development policies and procedures, to share knowledge and exchange experience and to represent rare disease patients at the national and European level.

If I am selected to attend the EURORDIS Summer School 2014:

- I agree to attend the full 4-day programme
- I agree to be included in EURORDIS list of potential volunteers so as to act as a rare disease patient representative for activities related to clinical trials and drug development.

As part of the EURORDIS list, I agree to:

- Share my knowledge
- Share my experience
- Be appointed as “patient expert” in particular for meetings at the EMA such as Protocol Assistance for my disease or review of European Public Assessment Reports
- To review EURORDIS’ position papers, contributions and statements for advocacy purposes in the clinical trial and drug development area
- Participate in other conferences and workshops
- I am interested in attending future capacity building sessions and seminars in orphan drug development organised by EURORDIS or third parties in conjunction with EURORDIS.

Signature

Date

Please fill out this form and send it back to nancy.hamilton@eurordis.org or fax +33 1 56 53 52 15