

APPLICATION FORM

Expert Patients and Researchers

EURORDIS Summer School

ExPRESS

Barcelona, Spain
June 1-5, 2015

Instructions for applicants:

1. The deadline for applications is **December 8, 2014**
2. This application form is divided into 3 Sections: **A, B and C.**
3. If you are applying as a patient representative, please complete sections **A and B.**
4. If you are applying as a researcher, please complete sections **A and C.**
5. Please write very clearly or type in your responses ensuring that your answers are complete and legible.
6. Please sign and date your application on page 4.
7. Only complete, signed and dated applications will be reviewed by the evaluation committee.
8. If you are applying as a patient, please send your completed form to nancy.hamilton@eurordis.org or fax to +33 1 56 53 52 15
9. If you are applying as a researcher, please send your completed form to a.m.aartsma-rus@lumc.nl

Section A (for all applicants)

a. Your contact details

First name		Last name	
E-mail		Telephone	
Address		Postal code	
City		Country	

b. Contact details in case of emergency

First name		Last name	
Telephone		Mobile phone	
Relation		Postal code	
City		Country	

c. English language skills

Tick the appropriate boxes

	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

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

Please describe past and current involvement in clinical trials and medicines development:

e. Medicines Development (10 lines max.)

Please describe any successful/unsuccessful current and foreseeable examples of collaboration between other stakeholders (research groups, patient organisations and/or pharmaceutical companies) in the field of medicines development in which you have been involved.

f. 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.

g. Please indicate 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

h. Commitment

Please evaluate your level of commitment to potentially be involved in clinical trial and medicines 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 Expert Patient and Researcher EURORDIS Summer School 2015:

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.

As one of the selected participants, I agree to:

- Attend the full 4.5 day programme
- Share my knowledge
- Share my experience
- 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. *(for patients only)*
- 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 *(for patients only)*
- To review EURORDIS' position papers, contributions and statements for advocacy purposes in the clinical trial and drug development area *(for patients only)*
- Participate in other conferences and workshops

Section B for Expert Patients only (Researchers, please go to section C)

a. Your patient organisation

(N.B. if your application is accepted, your organisation must be a member of EURORDIS, if it is not a member at the time of application, you will need to make a request for membership well in advance of the start of the Summer School.)

Name:

Disease(s) represented: (if applicable)

Type of organisation *(please tick only one):*
 Governmental Non-governmental/not-for-profit Educational/research institution
 Transnational/Intergovernmental Informal Other (please specify):

E-mail		Website	
Telephone		Fax	
Address		Postal code	
City		Country	

b. Your role in a patient organisation:

Are you? Please tick ✓ all that apply	Patient	<input type="checkbox"/>		Staff	<input type="checkbox"/>
	Family of patient	<input type="checkbox"/>		Volunteer	<input type="checkbox"/>

How long have you been active in the organisation?

What are your roles or activities?

Do you represent your organisation in any European Committee/Task Force/Working Group? If yes, please specify

What is your professional background?

Section C (For researchers only)

If you are a patient representative, please sign and date your application on page 4.

c. Your research organisation:

Name:

Your area of research:

Type of organisation (please tick only one):

- Governmental Non-governmental/not-for-profit Educational/research institution
 Transnational/Intergovernmental Informal Other (please specify):

E-mail		Website	
Telephone		Fax	
Address		Postal code	
City		Country	

d. Your role in your research organisation:

What is your current position?

Do you have a MD and/or a PhD?

Are you an early stage researcher (you obtained your PhD less than 5 years ago)?

What is your professional background?
(10 lines max.)

How long have you been involved in your current research field? What are your current roles and responsibilities?
(10 lines max)

Do you represent your organisation in any European Committee/Task Force/Working Group? (If yes, please specify e.g. IRDiRC working groups, European Networks or Consortia)

Are you a member of COST Action BM1207? "

Please sign and date your application form:

Signature

Date