

EJP RD

European Joint Programme on Rare Diseases

H2020-SC1-2018-Single-Stage-RTD
SC1-BHC-04-2018

Rare Disease European Joint Programme Cofund



Grant agreement number 825575

Del 15.6

Second Report on EURORDIS' Leadership Programme

Organisation name of lead beneficiary for this deliverable:

Partner 77 – EURORDIS

Due date of deliverable: month 60

Dissemination level: Public

Table of Contents

<i>Introduction and Objectives of the training</i>	3
<i>Training programme: definition of training content and methods</i>	4
<i>Programme Committee and speakers</i>	4
<i>Participants: applications and selection method</i>	4
<i>Participants: profile</i>	5
<i>Fellowships: process for attribution and results</i>	5
<i>Pre-training</i>	5
<i>Training delivery: programme outline</i>	5
<i>Training materials available</i>	8
<i>Evaluation: methodology and results</i>	8
<i>Dissemination</i>	9
<i>Conclusion and Next Steps</i>	9

Introduction and Objectives of the training

The rare disease community is currently experiencing a paradigm shift in the way healthcare and research are organised and delivered across Europe, as illustrated by the newly formed European Reference Networks (ERNs). The European Union Committee of Experts on Rare Diseases (EUCERD) highlighted in its recommendations on ERNs that patient representatives should have an integral role in the governance of ERNs.

Patients are expected to become more competent and credible leaders in this new landscape. Therefore, there is an urgent need to increase their capacity to be more effective leaders. This will depend on their abilities to build strong partnerships, to be seen as a credible partner, and to be able to represent the voice and needs of the rare disease community.

The needs are equivalent in research settings, throughout research projects and programmes. Integration of patient representatives within governance, advisory and steering committees of rare disease research and clinical research infrastructure projects will highly benefit from the development of the leadership and communication skills of patient representatives.

This leadership training aims to provide patient representatives, including but not limited to, European Patient Advocacy Groups (ePAGs) advocates involved in the 24 ERNs with a set of skills within leadership, design, training, coaching and communication. The programme will help nurture personal authority to better act on behalf of others, influence decisions and set the strategic direction within ERNs and European-wide disease specific and infrastructure research initiatives/projects. This will foster meaningful communication, cooperation, and coordination strategies and help patient advocates to carefully consider strategic health and research advocacy processes, roles, and responsibilities.

This task was originally to support the development of annual face-to-face 2 days training programme for 30 participants. The location were to be rotating each year: Barcelona (EURORDIS) in 2020 , Turkey (ACU/ACURARE) in 2021 and Italy (ISS) in 2022 and Poland (MUG) in 2023. However the 2021 edition was cancelled and the 2020 & 2022 editions were ultimately held online because of the Covid-19 pandemic. 60 applicants, rather than the original 30, were accepted to the 2023 in-person edition to compensate for the cancelled training.

Training programme: definition of training content and methods

The training for patient representatives and advocates on leadership and communication skills was organised for the first time in 2019, as a pilot edition. The specific training needs for this programme were identified in consultation with a working group of ePAG advocates as well as with several experts working with ERNs/ePAGs. All the trainers and contents were identified by EURORDIS with the support of rare disease and leadership experts.

The programme was improved in the following years, according to the feedback of participants, the development of ERNs and the role of patient advocates within the networks.

Programme Committee and speakers

A formal Programme Committee supported the development of the programme in 2020 and the identification of speakers, via ad-hoc consultations. Members of this group included EURORDIS staff, ePAG advocates, rare disease and leadership experts. 22 trainers/speakers were involved in the training edition, across the two training pathways, including several EJP partners. Most of these speakers were involved in the online training whereas 4 speakers conducted the onsite trainings (2 for each group).

Subsequent trainings (2022-2023) relied on the hosting partners institutions and networks to source trainers to address the subjects of the training.

Participants: applications and selection method

The applications for the training took place in January-April each year.

The application form was composed of questions/fields divided into the following main areas:

- Personal information, including disease/country, role as ePAG advocate and roles as patient advocate more broadly;
- Experience/knowledge in the training areas, previous training experience and motivation to attend the training;
- Information about the applicant's patient organisation and its relations to national alliances/European federations for rare diseases;
- Agreement to fully attend online training and face-to-face session;
- Consent for data processing in the scope of the review of applications.

The applications' review consisted of 3 phases:

- Exclusion of non-eligible applications.
- Scoring of applications by EURORDIS staff working with ERNs, ePAGs and training.

- Final selection: all the eligible applications were selected as

Participants: profile

	2020	2021	2022	2023
Participations at a glance				
Number of Participations - also on alumni file	28	NA	22	45
Eastern European Countries, Balkan and Caucasus*	4	NA	5	26
Nr of countries	12	NA	11	23
Nr of diseases	30	NA	16	36

Table 1: Participants profile in each of the workshop editions

Fellowships: process for attribution and results

8 fellowships are offered to patient advocates each year to attend the training in-person. This was not offered for the online editions. fellowships were offered in 2023.

The fellowship applications were incorporated into the application process and selection took place at the same time as of attendees. The fellowships were attributed in accordance to the EURORDIS [fellowship evaluation scale available here: Fellowship application evaluation scale updated090922.docx](#)

Pre-training

The pre-training allows trainees to familiarise themselves with the concepts and terminology that is used during the onsite training. It consists of various webinars across the different years depending on the planning of the session and availability of speakers.

Training delivery: programme outline

2020

EURORDIS Leadership School 2020	
Webinars	Intensive online training
Duration: 20hrs, webinars + preparation/follow up	Duration: 12hrs, over 3 half days
Dates: April to November 2020	Dates: 6-8 October 2020
Training topics and schedule: <ul style="list-style-type: none"> • Introduction: 21 April, 16-17:30 CET • 360° Self-awareness: 30 April, 16-17:30 CET • Emotional Leadership: 26 May, 16-17:30 CET 	Training topics: <ul style="list-style-type: none"> • Power and Influence Workshop • Insightful Influencing • Physiology of Status and Authority • Psychology of Status and Authority • Applying framework to difficult situations • Emotionality of Status and Authority

<ul style="list-style-type: none"> ● Creating value from your experience: 30 June, 16-17:30 CET ● Maximising your communication & impact: 14 July, 16-17:30 CET ● Multicultural awareness & European dimension: 17 September 11-12:30 CET ● Reflection session: 14 October 16:30-17:30 CET ● Conflict Resolution: 22 October, 18-19:30 CET ● Negotiation: 17 November, 16-17:30 CET 	<ul style="list-style-type: none"> ● Relational Dynamics ● Practising Influencing <p>Presenting with impact</p> <ul style="list-style-type: none"> ● Warm up and Theory re-call ● Work on Speeches: Emotions & Characters ● How to give & receive feedback ● Presentation of speeches and feedback ● Awareness exercise ● Review of selected speeches & presentation in plenary
---	--

Table 2: Programme outline of 2020 training edition

2022

EURORDIS Leadership School 2022	
Day 1 November 10, 2022	Day2 November 11, 2022
<ul style="list-style-type: none"> ● European Reference Networks (ERNs): overview & success so far and important issues for the future ● Integration of ERNs into national level Marfa Mosca, Domenica Taruscio ● The Role of EURORDIS ● The Role of National Alliances: the Italian Experience "UNIAMO" ● The role of ePAGs within the ERNs - Managing patient engagement in the ERNs ● The active and pro-active role of e-PAGs ● How to link multi-level patient representation ● The role of ePAGs within the community ● Round table: leading within the ERN / engaging with the community of healthcare providers 	<ul style="list-style-type: none"> ● Public speaking (interactive morning session) ● Negotiation skills (interactive morning session)

Table 3: Programme outline of 2022 training edition

2023

Webinars:

Time	Session and Trainer(s)
Wednesday 27th September 12:00-13:30	360° Self-awareness Concha Mayo, EURORDIS
Wednesday 11th October 12:00-13:30	Emotional Leadership Concha Mayo, EURORDIS

Face-to-face training programme:

Thursday 26th October

Time	Session and Trainer(s)
09:00-9:30	Joint Welcome & Introduction Rachel Butcher, Open Academy Training Manager, EURORDIS Dr Karolina Śledzińska, Medical University of Gdańsk Prof. Jolanta Wierzbą, Medical University of Gdańsk
9:30-10:45	How to build a team, not destroy it? Dr Iwona Simion, Foundation for Developmental Support ME TOO
10:45-11:15	Coffee break
11:15-12:30	Burnout aid (recognition and recovery) Dr Agata Zdun-Ryzewska, Medical University of Gdańsk
12:30-14:00	Lunch Break
14:00-17:00	Negotiation skills – How to negotiate with public partners Dr Michał Brzeziński, Medical University of Gdańsk OR Wealth of information creates a poverty of attention – How to talk so that everyone will listen Tomasz Grybek, Foundation of Borys the Hero (Sessions running in parallel with coffee break)
17:30	Visit to European Solidarity Centre & Welcome Dinner at AmberSide Transportation provided

Friday 27th October

Time	Session and Trainer(s)
09:00-9:30	Introduction to ePAGs Tomasz Grybek, Foundation of Borys the Hero
9:30-10:45	How to identify problems/conflicts within the community (health systems, social care etc.) Dr Katarzyna Mińska-Musa, Medical University of Gdańsk
10:45-11:15	Coffee break
11:15-12:30	Advocacy – how to talk about rare diseases with different groups of interlocutors Kasia Świeczkowska, Polish Association for Persons with Intellectual Disability
12:30-14:00	Lunch Break
14:00-17:00	Negotiation skills – How to negotiate with public partners Dr Michał Brzeziński, Medical University of Gdańsk OR Wealth of information creates a poverty of attention – How to talk so that everyone will listen Tomasz Grybek, Foundation of Borys the Hero (Sessions running in parallel with coffee break)
17:00-17:30	Wrap-up session Organisers and available speakers

Table 4: Programme outline of 2023 training edition

Training materials available

The pre-training webinar recordings and presentations (including recordings in the case of the online editions) were made available to the participants after the training. These are available to EJP partners on demand.

Evaluation: methodology and results

The evaluation of the programme is conducted via feedback questionnaires, filled in online and anonymously. On the last training day, participants receive the overall feedback questionnaire, including questions on the impact/value of the training, on the pre-training and on the preparation/logistics.

2020

The rate of response to the evaluation questionnaires was of 50%.

- 100% of respondents stated that they would recommend the Leadership School to other patient representatives.
- 100% agreed that the Leadership School effectively builds the capacity of patient advocates on leadership topics and skills (82% strongly agreed; 18% agreed);
- 100% found the topics relevant for their activity as patient advocate (77% strongly agreed; 23% agreed);
- 100% considered that the training provided them with essential knowledge and tools to support them in representing patients in activities related to ERNs (54% strongly agreed; 46% agreed);

2022

The response rate to the evaluation questionnaire of the online edition of the training has been of 73%

- 94% of the respondents thought the aims of the training were clearly defined.
- 87% of the respondents stated the event increased their knowledge.
- 100% of the respondents stated the displayed materials were explanatory and of good quality.
- 69% of the respondents thought the event was well organized.

2023

The rate of response to the evaluation questionnaire was 62%.

- 96% of the respondents thought the aims of the training were clearly defined.
- 89% of the respondents stated the event increased their knowledge.
- 96% of the respondents stated the displayed materials were explanatory and of good quality.
- 96% of the respondents thought the event was well organized.

Dissemination

The applications for the trainings were widely disseminated via EURORDIS & partners, via social media as well as via the EJP's communication tools and partners.

Conclusion and Next Steps

After year 5, the integration of leadership training into other programmes, such as Task 15.1 and 15.2 will be considered. Currently there are no plans to continue the Leadership training in its current format.

