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First Report on EURORDIS's Leadership Programme

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Introduction and Objectives of the training

Based on EJP application and updated description for year 2 WP:

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 in ERNs' governance structures. 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 will support the development of the annual face-to-face 2 days training programme for 30 participants. The location will be rotating each year: Barcelona (EURORDIS), Italy (ISS), Turkey (ACU/ACURARE) and Poland (MUG).

In 2019, EURORDIS organised this programme for an additional group of 30 ePAG advocates, supported by other funding sources. Each group had its training pathway, both trainings running in parallel. The onsite training took place at the same date and location for both groups. For this reason, the programme of 2019 was labelled as "EURORDIS Leadership School", to facilitate recruitment and communication with the patient community.

Although only 30 participants were allocated to the EJP funding (*Advocates Group - see point 4*), this report includes the outcomes for both groups, to best describe the programme and demonstrate the impact of this pilot edition.

The learnings from this pilot edition will be used to improve and adjust the programme in 2020, both on the EJP funded training as well as other leadership trainings organised by EURORDIS.

1. 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 will be improved in the following years, according to the feedback of participants, the development of ERNs and the role of patient advocates within the networks.

2. Programme Committee and speakers

An informal Programme Committee has supported the development of the programme in 2019 and the identification of speakers, via ad-hoc consultations. Members of this group included EURORDIS staff, ePAG advocates, rare disease and leadership experts. A formal Programme Committee is to be established in 2020, to support the review of the programme and the identification of trainers/speakers.

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).

3. Participants: applications and selection method

The applications for the training took place in January-February 2019. EURORDIS received a total of 61 applications, across the two training groups.

58 patient advocates were initially selected to attend the programme – 29 in each group. The remaining 3 applications were not eligible. There was no waiting list for this training.

The application form was composed of over 30 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 they amounted to less than 30 for each group.

4. Participants: profile

56 participants attended the training in 2019, divided in two groups with distinct training pathways:

- Advocates Group (28): ePAG patient advocates active in their own disease area, involved in a disease-specific core network and in topic-based working groups within their ERN;
- New Leaders Group (28): ePAG patient advocates who are leaders representing the wider patient community in ERN Boards and in topic-based working groups.

These patient advocates represented 17 countries, 21 European Reference Networks and over 45 rare diseases.

The countries represented were the following: Austria, Belgium, Czech Republic, Denmark, France, Germany, Greece, Ireland, Italy, Netherlands, Norway, Portugal, Romania, Spain, Sweden, Switzerland and United Kingdom.

The participants represented the following ERNs: ERN BOND, ERN CRANIO, Endo ERN, EpiCARE, ERKNET, ERN EYE, ERN GENTURIS, ERN RITA, ERN Skin, ERNICA, ERN-LUNG, ERN-RND, EURACAN, eUROGEN, EURO-NMD, Guard-Heart, ITHACA, MetabERN, ReCONNET, TransplantChild and VASCERN.

Rare diseases represented included e.g.: Achondroplasia, Alkaptonuria, Congenital Heart Disease, Septo Optic Dysplasia, Cystic Fibrosis, Duchenne Muscular Dystrophy, Ehler-Danlos-Syndrome, Epidermolysis bullosa, Gaucher disease, Hereditary Hemorrhagic Telangiectasia, Interstitial Cystitis, Marfan Syndrome, Myasthenia gravis, Neurofibromatosis, Osteogenesis Imperfecta, Pitt-Hopkins syndrome, Idiopathic Pulmonary Fibrosis, Ring Chromosome 20 Syndrome, Spina Bifida, Spinal Muscular Atrophy and Vasculitis.

Of the 56 participants, 38 attended the onsite training: 20 in the Advocates Group and 18 in the New Leaders group. Most of the patient advocates who were not able to attend the onsite training were facing urgent health or caring needs. A few patient advocates could not attend due to overlapping activities within their ERN/ePAG or professional life.

From the feedback of participants (see point 9) and from the organising team, it was acknowledged that the programme was quite dense and intense, being difficult to combine with personal and professional commitments.

The programme will be adjusted in 2020, based on this feedback, in view of ensuring maximum attendance rate of the onsite training.

5. Fellowships: process for attribution and results

7 patient advocates received a fellowship to attend the training in 2019: 4 in the Advocates Group (EJP funded, with a total of 1000€) and 3 in the New Leaders group (covered by other funding source). The fellowship receivers came from France, Belgium, Switzerland and United Kingdom, in the case of the Advocates Group; and from Netherlands, Germany and United Kingdom, in the case of the New Leaders group.

The fellowship applications took place in July 2019. The fellowships were attributed in accordance to the EURORDIS fellowship evaluation scale available [here: https://openacademy.eurordis.org/wp-content/uploads/2019/07/EURORDIS-Open-Academy_Fellowship-application-evaluation-scale.pdf](https://openacademy.eurordis.org/wp-content/uploads/2019/07/EURORDIS-Open-Academy_Fellowship-application-evaluation-scale.pdf).

6. Online training

The online training was an essential component of the programme. It served to directly train the participants on various important topics in leadership, on healthcare and research. It also served to optimise the onsite training, allowing participants to be more active in the leadership exercises done face-to-face.

The online training took place April to October 2019 and included a total of 20 webinars: 15 attended by the Advocates Group and 10 attended by the New Leaders Group (5 webinars were for both groups together). The webinar recordings were shared with all the participants afterwards.

The training schedule and topics for each group are presented below:

Training Topics	Courses – Webinars	Target Trainees	Time frame	Total training time
Leadership	<i>1 webinar per topic</i> 1. 360° Self-awareness 2. Model Leaders 3. Good Communicator 4. Presenting with Impact 5. Conflict Resolution Strategies	Advocates Group New Leaders Group	April-May	12h30
	<i>1 webinar per topic</i> 1. Creating Authority and Legitimacy 2. Influencing Without Authority 3. Negotiation 4. Programme Management 5. Network Governance & Assurance	New Leaders Group	June-Sept.	12h30

Technical knowledge	<p>2 webinars per topic</p> <ol style="list-style-type: none"> 1. Networks 2. eHealth 3. Knowledge Generation 4. Research 5. Healthcare 	Advocates Group	June-Oct.	25h
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7. Onsite training delivery: programme outline

The face-to-face training took place on the 26th and 27th of November 2019, in Barcelona. The 2 day programme included a series of interactive sessions, with work in small groups, role playing and varied leadership exercises.

The outline of the onsite programme for the Advocates Group was the following:

- Tues, 26: Good Communicator - including active listening, observing, describing, asking and creating rapport;
- Wed, 27: Presenting with Impact - including body and voice activities, preparation and presentation of speeches.

The full onsite programme for the Advocates group can be found [here](https://openacademy.eurordis.org/wp-content/uploads/2019/12/EURORDIS-Leadership-School-2019_Advocates_Programme.pdf): https://openacademy.eurordis.org/wp-content/uploads/2019/12/EURORDIS-Leadership-School-2019_Advocates_Programme.pdf.

The outline of the onsite programme for the New Leaders Group was the following:

- Tues, 26: Creating Authority and Legitimacy – including power and influence, psychology, character, physiology and chemistry;
- Wed, 27: Influencing Without Authority – concepts on including influencing, creating content and practicing influence with scenarios.

The full onsite programme for the New Leaders group can be found [here](https://openacademy.eurordis.org/wp-content/uploads/2019/12/EURORDIS-Leadership-School-2019_New-Leaders_Programme.pdf): https://openacademy.eurordis.org/wp-content/uploads/2019/12/EURORDIS-Leadership-School-2019_New-Leaders_Programme.pdf.

8. Training materials available

The webinar recordings and presentations of the online training were shared with all the participants and with the faculty.

The onsite training was based mostly on practical exercises. There were only two presentations, delivered to the Advocates Group. These were made available to all participants ahead of the training.

All the presentations are available to EJP partners on demand.

9. Evaluation: methodology and results

The evaluation of the programme is conducted via feedback questionnaires, filled in online and anonymously.

At the end of each webinar and of each onsite training day, the participants receive a short questionnaire via which they are required to indicate if it was “informative”, “relevant” and “too technical”.

In September, the participants were asked to provide their feedback on the structure of the online training - e.g. number of webinars, frequency, length - in order to support the start of the planning for 2020.

At the end of the onsite training, participants also received the overall feedback questionnaire, including questions on the impact/value of the training, on the online training and on the preparation/logistics.

The rate of response to the evaluation questionnaires in 2019 was of 80% for the Advocates Group and 100% for the New Leaders Group.

The main results include:

- 100% of the respondents in both groups stated that they would recommend the Leadership School to other patient representatives and researchers;
- 93% of the Advocates Group and 89% of the New Leaders group found that the EURORDIS Leadership School effectively builds the capacity of patient advocates on leadership and on healthcare/research topics relevant to ERNs (*strongly agreed, agreed*);
- 93% of the Advocates Group and 94% of the New Leaders have found the topics relevant for their activity as patient advocates (*strongly agreed, agreed*);
- 87% of the Advocates Group and 83% of the New Leaders considered that the training provided them with essential knowledge and tools to support them in representing patients in activities related to ERNs (*strongly agreed, agreed*).

Regarding the feedback on the structure of the programme, it has been acknowledged that the programme was quite dense and intense, being difficult to combine with personal and professional commitments. The following points for improvement were suggested by the participants and the organising team to ensure maximum attendance rates to the online and onsite training:

- Reducing the number of webinars and increasing the time between each webinar;
- Providing training in e-learning format instead of live webinars, to allow participants to follow the training according with better balance between their professional, patient advocate and personal activities;
- Avoiding overlap between the webinar topics and the onsite training.

The reports on the feedback from participants are being used to improve the programme for the 2020 edition.

10. Dissemination

The applications for the EURORDIS Leadership School were widely disseminated to all the ePAG advocates. A series of social media posts were disseminated during the training, under the hashtag #EURORDISLeadershipSchool.

Photos from the onsite training sessions are [available here: https://www.flickr.com/photos/eurordis/sets/72157711288690948/with/48879224578](https://www.flickr.com/photos/eurordis/sets/72157711288690948/with/48879224578).

11. Conclusion and Next Steps

The lessons learnt from this pilot training for patient advocates on leadership are crucial to adjust the training programme in 2020, both in regards to the EJP supported actions, as well as in regards to complementary leadership training organised by EURORDIS.

The feedback from participants on the programme structure and content is an important basis to shape the future leadership trainings.

The EJP task partners will also be providing input in regards to the future programme, as hosts of the upcoming face-to-face sessions. A call with the EJP task partners is to be scheduled in early 2020.

The planning for the timeline of activities and of the programme structure will be concluded by end of February 2020.

Indicators

WP	Action/Activity	Result	Indicator	How is the indicator measured?	Target/threshold	Results Year 1, 2019	Indicator type	Who measures the indicator?	Who reviews the Indicator
WP 15.3	Training delivery	Pre-training and training webinars and online courses	All planned webinars and online courses	Number of webinars and courses actually delivered	5 webinars in 2019; 1 webinar and 2 courses from 2020	20 webinars	KRI	EURORDIS Open Academy Director	Pillar 3 and WP15 leader (EURORDIS Scientific Director)
WP 15.3	Training quality	Programme Committees engagement	All planned consultations with Programme Committees	Number of calls, email consultations, etc. to Programme Committees	2 calls 1 email consultation	To start from 2020	KRI	EURORDIS Open Academy Director	Pillar 3 and WP15 leader (EURORDIS Scientific Director)
WP 15.3	Training quality	Programme Committees contribution to training programmes	All recommendations implemented in online and/or face to face training courses	Number of reviews of the programmes integrating programme committees' feedback	1 annual review	1 annual review	KPI	EURORDIS Open Academy Director	Pillar 3 and WP15 leader (EURORDIS Scientific Director)
WP 15.3	Training quality	Review of pre-training and online courses according to alumni's feedback	All planned evaluation and annual follow-up with participants	Rate of satisfaction of participants regarding usefulness of the pre-training (Q: <i>The training provided me with essential knowledge/tools to support me in representing patients in activities related to ERNs. Rate of satisfaction combines "Strongly Agree"/"Agree". A question on usefulness of the online training will be added in 2020</i>)	60%	87% of the Advocates Group 83% of the New Leaders	KPI	EURORDIS Open Academy Director	Pillar 3 and WP15 leader (EURORDIS Scientific Director)
WP 15.3	Training impact	Review of impact of the training on individual participants	All planned evaluation and annual follow-up with participants	Percentage of participants considering that the training effectively builds their capacity and/or provides essential knowledge and tools for their own activities (Q: <i>The training effectively builds the capacity of patient advocates on leadership and on healthcare/research topics relevant for ERNs. Rate combines "Strongly Agree"/"Agree"</i>)	70%	93% for the Advocates Group 89% of the New Leaders group	KRI	EURORDIS Open Academy Director	Pillar 3 and WP15 leader (EURORDIS Scientific Director)