

ERN Support and Training programme- WP17- EJP RD

Report Workshop “Advances in regenerative medicine and tissue engineering for rare Musculo-skeletal diseases”

Date/Venue/Format

13-14 October 2023, Sala Italia – Centro Congressi Università Cattolica del Sacro Cuore, Rome, Italy

Numbers (participants, speakers, ERNs represented, patient representatives)

The event was attended by a total of 38 people including:

- 18 participants
- 20 speakers
- 11 ERNs were represented: ERN ITHACA; ERN EpiCARE; ERN-RND; ERN GENTURIS; ERKNet; ERN CRANIO; ERN EuroBloodNet; ERN eUROGEN; ERN EURO-NMD; ERN-BOND; ERN-ReCONNET
- Representative from 3 patient advocacy associations (European Patient Advocacy Groups – ePAG representative; Italian Federation of Rare Diseases UNIAMO; Federazione GENE per la Neurochirurgia Infantile) took part in the event as speakers.

Analysis of the workshop satisfaction survey

The survey was completed by 27 participants, including both attendees and speakers, and allowed assessing an overall very high satisfaction about the quality and efficiency of the event.

- The quality of the workshop was rated between “very good” and “excellent”, with 82% of respondents choosing “excellent”.
- The workshop contents for research/professional activities emerged as “useful” (22%) or “highly useful” (78%).
- The training contents were considered “just right” for the level of knowledge and expertise, with the exception of one that was evaluated as “too easy/basic” and another as “too difficult/complex”.
- The respondents appear to be “satisfied” (37%) or “very satisfied” (63%) about the date and time planning.
- They appeared to be “satisfied” (18%) or “very satisfied” (82%) about the connection process, and “satisfied” (22%) or “very satisfied” (78%) about the quality of the speakers.
- The respondents appeared “satisfied” (11%) or “very satisfied” (89%) regarding the organisation (agenda, information delivery, support



- during the meeting); they also reported to be (“satisfied” (7%) or “very satisfied” (93%) about the structure of the programme.
- As for the workshop location, the feedback indicated satisfaction levels ranging from “satisfied” to “very satisfied”, except for one respondent who evaluated it as “neither satisfied nor dissatisfied”.
 - The survey responses revealed that the majority of participants expressed a preference for future courses either “face-to-face” (81.5%) or with “no preference” (15%), while only one respondent stated a preference for “online” courses.
 - 96% of the respondents “agree” or “strongly agree” that the workshop allowed to interact satisfactorily, except for one respondent who stated “either agree nor disagree”.
 - All the respondents “agree” or “strongly agree” that there was enough time for Q&A, that the workshop allowed to gain better understanding in the topic, and that there were appropriate learning objectives set.
 - The 93% of the respondents “agree” or “strongly agree” that the learning objectives have been met, except for two respondents who stated “either agree nor disagree”.
 - Regarding the possible use of the contents learned during the workshop regularly, i.e. at least monthly in your working routine, 52% of respondents answered “Yes”, 44% “Maybe” and 4% “No”.
 - The importance of CME points for this kind of training events was evaluated as “extremely important” by 21% of respondents to this issue, “irrelevant” for the 17% and “neutral” for the 62%.

In addition, the multidisciplinary of the topics discussed and how they were approached from different perspectives were particularly appreciated. Suggestions have been made for the delivery of supplementary materials prior to the talks, additional reminders of the date and time of the workshop, and the projection of some videos to enhance focus on specific aspects.

2-3 participants' testimonials

Mariët Faasse, ePAG representative, commented enthusiastically about the training, stating that “It was interesting to see that we are all working towards the same bigger aim from different perspectives, it was a great opportunity to learn from each others' 'world'.”

Alessia Vita, attendee, described her impressions after attending the workshop as follows: “Working in the field of bone tissue, I found particularly useful and stimulating the sessions on advances in bone tissue engineering, in particular for the use of biomaterials through bioprinting. A brand new perspective was provided thanks to the integration of cross-domain expertise



from the regulatory field along with the interesting insights into patients' standpoint."

The event was widely disseminated by the institutional press office at <https://secondotempo.cattolicanews.it/news-la-medicina-rigenerativa-per-la-cura-delle-malattie-rare-muscolo-scheletriche> and on social media (LinkedIn , Facebook, Instagram): https://www.linkedin.com/posts/wanda-lattanzi-3940b020_rarediseases-ejprd-research-activity-7119019380562157568-A3nm?utm_source=combined_share_message&utm_medium=member_desktop ; https://www.linkedin.com/posts/annalisa-scopinaro-51322b113_gemelli-activity-7118557387703091202-8sjd?utm_source=share&utm_medium=member_desktop ; https://www.linkedin.com/posts/wanda-lattanzi-3940b020_a-big-special-thanks-to-our-colleague-marta-activity-7119398845821693952-UUAY?utm_source=share&utm_medium=member_desktop ; https://www.instagram.com/p/CyblxNGqSO-DIVeY24xRpd860aU6mOyOk_6_VI0/ ; https://www.instagram.com/p/CybjqoYKR0DUM2bU61_xyUPWm68eb59QBY6q5c0/ ; <https://www.instagram.com/p/CybjE6rqWBIQyPbDh0wompFn1YehpcXoCisu3s0/> .

If applicable a main result of the workshop (e.g. working group created to do xxxx)

Not applicable

Conclusions, lessons learned, best practice to keep in mind.

Overall, the workshop has been highly satisfactory in terms of results and feedback obtained. It served as an excellent training opportunity that brought together various perspectives from basic research, emerging technologies, clinical needs, and the patient's viewpoint represented by organizations. It was beneficial to involve speakers with diverse expertise, which significantly expanded the range of participants between PhD students, postDoc, researchers, clinicians, resident fellows, specialized paramedics, as well as different ERN communities. It also provided an excellent networking and sharing opportunity, facilitating both the consolidation of existing collaborations and the establishment of new partnerships. The networking dinner facilitated interactions in an informal setting and undoubtedly represents a strong point of these initiatives.

