

Engagement Visit Suomen Reumaliitto Ry – Finnish Rheumatism Association

27 – 29 November Finland

Introduction

The EULAR PARE Engagement programme has been redesigned from the previous PARE country visits to improve procedures from application to performance as well as monitoring and evaluation processes. A formal report on procedures and overall programme setup will be finalised in March 2016.

This first visit to the [Finnish Rheumatism Association](#) took place from 27 – 29 November. The visit took place in the headquarters of the association, the national parliament (Helsinki) and at the Joy for Life event (children and parents). (Appendix I – Overview event & schedule)

Aim / Objectives event specific

- Identifying successful, transferable activities and concepts by gaining an overview of structure and activities of [Finnish Rheumatism Association](#).
- Developing ideas for pan European initiatives by building personal relationships and gaining insights into other (e.g. Sweden, UK) PARE organisations' plans.
- Fostering national collaboration by providing European perspective in national meeting with Health professionals, doctors, politicians and other interested stakeholder organisations.
- Share detailed knowledge about EULAR organisations' programmes and capacities

Association profile

The [Finnish Rheumatism Association](#) was founded in 1947, has 159 local member associations with 41 000 individual members. It holds the secretariat offices for the umbrella for rare diseases and several other disease specific organisations. The association currently aims to tackle declining membership and an old fashioned public image.

On Public affairs and campaign level the organisation is part of [SOSTE](#) the Finnish Federation for Social Affairs and Health (202 NGO members) and part of the Steering group of [POTKA](#) the network of patient organisations (combining 42 patient organisations with 500.000 members, 10% of Finland's population).

Executive Summary

EULAR PARE contacted and requested to visit the Finnish EULAR member PARE organisation in June 2015. Detailed planning took place mainly between October and end of November (Appendix I – Overview event & schedule).

Preliminary evaluation concludes this visit was a success. Mutual learning has taken place with the interest for closer interaction in the future. Areas have been identified where synergies could be realized and transferable best practices should be shared.

The profile of the organisation has been raised not only on Social Media (Facebook and Twitter) but also to members of the Finnish parliament. EULAR's profile has been raised through detailed interaction between key staff & all elected representatives of Suomen Reumaliitto Ry. Follow up actions and expected long term outcomes will be outlined at the end of the report. It is recommended to evaluate this after 12months again.

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- Identifying successful, transferable activities and concepts by gaining an overview

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of structure and activities of Finnish Rheumatism Association.

- Developing ideas for pan European initiatives by building personal relationships and gaining insights into other (e.g. Sweden, UK) PARE organisations' plans.
- Fostering national collaboration by providing European perspective in national meeting with health professionals, doctors, politicians and other interested stakeholder organisations.

Evaluation

Identifying successful, transferable activities and concepts by gaining an overview of structure and activities of Suomen Reumaliitto ry.

Presentations by Miranna Seppälä-Saukkonen "How does the Finnish Rheumatism Association Lobby" Sini Hirvonen "[youth and family activities](#)", and a broad overview on main aims and structures by CEO Maria Ekroth showed clearly there is MUCH more information to gain – impossible to transport this in 1.5days.

Follow up

EULAR and Suomen Reumaliitto Ry will exchange to share the associations` activities over the next 12 months.

Requested information (if possible) to be sent to Finnish Rheumatism Association immediately:

- Arthritis Ireland's (AI) presentation on how public perception of AI was changed
- AI's presentation on campaign "I have Arthritis but Arthritis doesn't have me"
- List of liaison emails of PARE organisations to foster independent member organisations' communication.

Further thoughts: It was discussed how it would be possible to enable organisations to better connect and plan with each other to reduce duplication of messages, work development of campaign material, especially around awareness raising campaigns, policy and public affairs work. Furthermore it was discussed how best practices can be effectively shared among organisations to create added value.

All of EULAR PARE activities were presented and will be again sent via email to deepen the learnings.

Developing ideas for pan European initiatives by building personal relationships and gaining insights into other (e.g. Sweden, UK) PARE organisations' plans.

- CEO meeting is a key event to discuss European ideas
- WAD Video campaign 2017 means a start to harmonise actions
- The Finnish Association is interested to engage 3-5 organisations to plan projects together and apply for EULAR and external funding
- World Arthritis Day plans should be planned much earlier in advance with agreement by at least some organisations with 5 year plans for realising synergies

together in the future

Fostering national collaboration by providing European perspective in national meeting with Health professionals, doctors, politicians and other interested stakeholder organisations.

PART I Political

On Public Affair level the organisation is well connected, a parliamentary interest group on RMDs recently has been established recently with members of the main parties included.

On Public affairs and campaign level the organisation is part of [SOSTE](#), the Finnish Federation for Social Affairs and Health (202 NGO members) and part of the Steering group of [POTKA](#) the network of patient organisations (combining 42 patient organisations with 500.000 members, 10% of Finland's population).

The political part of the visit was done with minimal preparation and was deemed not as highly important by the Finnish Rheumatism Association, an informal meeting with two Members of Parliament were planned of which one ([Arto Satonanen](#)) could be realised.

The Finish health care system is under financial pressure and spending cuts are to be expected. The EULAR PARE delegation visited the Finish Parliament to discuss EULAR Charter for Work: People with RMDs in Europe". The main message was that "Investing in prevention is key when redesigning Finnish health care system to implement person centred-care".

Part II Collaboration with other organisations

A meeting with a consultant rheumatologist (in training) took place to gain an overview of the health care practices in Finland. Specifically the role of the patient in #shareddecisionmaking and the use of Biologics vs Biosimilars were discussed. The Finnish Association follows the advice by the Finnish Society of Rheumatology which sees no difference in the use of Biosimilars vs Biologics. Further evaluation is also pending in Finland awaiting results from Norswitch.

Share detailed knowledge about EULAR organisations' programmes and capacities

Additionally to the above mentioned items, summarising the discussions that took place during the days as well as detailed information given in the presentation (Appendix 2) show that this knowledge and the suggested follow up led to a successful achievement of this objective.

Follow up

Send EULAR Charter for Work to members of Finnish parliament (CEO Maria Ekroth)

Social media outreach

The whole event, especially the visit in the parliament was documented on Social media – EULAR scheduled a Tweet and Facebook post on the Political meeting.

(#EULARPARE, #Finnishparliament

(@EkrothMaria, @Reumaliitto @eular_org @EduskuntaRblx @Kouloumasm @artosatonen)

Long Term measurements of success

The event will be evaluated in 12 months (November 2016) and should result in

- 1 Article in Breakthrough Newsletter as report on visit by PARE Board
- 1 application to Knowledge Transfer programme
- 1 abstract submitted to EULAR

Conclusion

The political part of the visit was done with minimal preparation and still it was possible to support the Finnish Association in their role as competent advisor on health care issues. Social media exploitation was done with preparation and agreement of EULAR's and the Finnish Associations communication officers, raising the profile of both organisations.

Developing relationships with and between organisations is clearly an area which could be improved. The role of the liaison person in an organisation needs to be supported by additional measures such as

- Area specific information and responsible liaisons in organisations
- Concerted message sharing between organisations
- More ties between organisations generally
- A platform to share information enabled by EULAR
- Webinars as learning and teaching organisations sharing expertise
- face to face visits ideally to foster personal relationships

The Finnish Rheumatism Association gained qualitative information through PARE's presentation, all of which had been sent numerous times but did not sink in fully until it was supported by a face to face meeting. Long term evaluation will be provided in November 2016.