



QSPainRelief

Effective combinational treatment of chronic pain in individual patients, by an innovative quantitative systems pharmacology pain relief approach.

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D9.3 – 1st Patient and Layman Event

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Abbreviations

ACN	Active Citizenship Network
CEO	chief executive officer
concentris	concentris research management GmbH
COVID-19	coronavirus disease 2019
ELENA	Hellenic League against Rheumatism
ENFA	European Network of Fibromyalgia Associations
FBPF	Federation Bulgarian Patients Forum
FES	Fibromyalgie en Samenleving
IPBF	International Painful Bladder Foundation
IIB	Impact (and Innovation) Board
ISAL	Istituto di Formazione e Ricerca in Scienze Algologiche
ISB	In Silico Biosciences, Inc.
LRG	Galician Rheumatological League
MeR	Myeloma Euronet Romania
PAE	Pain Alliance Europe
PMO	project management office
ppt	Microsoft® PowerPoint
PU	public
SC	Steering Committee
SEAB	Scientific and Ethical Advisory Board
UCL	Université Catholique de Louvain
UK	United Kingdom
ULEI	Universiteit Leiden
WP	Workpackage

Author list

Organisation	Name	Contact information
04 concentris	Nina Donner	nina.donner@concentris.de
01 ULEI	Liesbeth de Lange	ecmdelange@lacdr.leidenuniv.nl
02 ISB	Robert Carr	Robert-Carr1@In-Silico-Biosciences.com
08 UCL	André Mouraux	andre.mouraux@uclouvain.be

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1 Executive summary

A key aspect of QSPainRelief's dissemination strategy and its communication goals is to make the project's approach and methods, and eventually also its results and regulatory impact known to the general public and the pain patient community. At this stage of the project, our focus lies on making the project's scope and approach known as widely as possible to the general public and to patients within Europe that suffer from chronic pain. Besides (1) connecting to local, national, and international pain patient organisations on social media, and gaining their attention with frequent posts and tweets, we will (2) make QSPainRelief dissemination items (press releases, poster, info brochure, roll-up banner, ppt talks, webinars, videos etc.) publicly available in easy-to-understand layman terms via the project website, and, most importantly, (3) engage directly with chronic pain patients or their representatives via QSPainRelief's patient & layman events. Since Pain Alliance Europe (PAE) is an important member of QSPainRelief's Scientific and Ethical Advisory Board (SEAB), and kindly agreed to support the project's dissemination activities as much as possible through their existing channels, we planned the first patient & layman event jointly with PAE's Annual General Assembly (GA) Meeting.

Due to the COVID-19 pandemic, the first patient & layman event took place in virtual form on Wednesday, 24 June 2020: Upon invitation by PAE's president, Joop van Griensven, and the meeting organizing team, Prof. Dr. Liesbeth de Lange gave a 30 min ppt presentation about QSPainRelief, followed by time for questions and interaction, as the closing lecture of PAE's GA Meeting. The audience consisted of 23 layman and representatives of 19 national pain patient organisations from 13 different European countries.

The presentation was well-received by all meeting attendees. Upon multiple requests from the audience, Lisbeth's talk will also be recorded and shared as a webinar on the project website within the coming months. In conclusion, the event greatly increased the project's reach and dissemination potential. This was reflected as an increase in followers on social media and an increased number of website visits and page views immediately after the event.

2 Deliverable Report

2.1 Planning and Announcement of Event

The project management office (PMO), consisting of Liesbeth de Lange from Universiteit Leiden (ULEI) and concentris research management GmbH (concentris) as well as Robert Carr (the chair of the Impact and Innovation Board (IIB), and CEO of In Silico Biosciences, Inc. (ISB)) and André Mouraux from Université Catholique de Louvain (UCL) prepared the event in collaboration with PAE, and announced it via PAE's and QSPainRelief's social media channels and on the project website (qspainrelief.eu).



Figure 1. Announcement of 1st patient event by Pain Alliance Europe (PAE) and via the project's social media accounts ([LinkedIn](#) and [Twitter](#)) and via the project website.

2.2 Preparation of the Presentation and Execution of Event

Since the first day of the 2nd Steering Committee (SC) Meeting took place in virtual form via the online-tool 'GoToMeeting' on 23 June 2020, Liesbeth had time to give a practice presentation in front of all attending SC members. This allowed her to integrate valuable feedback from the team prior to the event. In addition, concentris revised the presentation with supporting visuals and graphical design features.

On 24 June 2020, concentris (Nina Donner and Sara Stöber) and Liesbeth de Lange (ULEI) joined PAE's GA Meeting from 2:30 to 3:30 pm. During this time, Liesbeth de Lange gave the 30-min ppt presentation about QSPainRelief in layman vocabulary to illustrate the underlying problem, the scope of the project, the novelty of the approach, and what QSPainRelief aims to achieve. The talk was scheduled as the closing lecture of PAE's GA Meeting which (due to corona) took place in virtual form via the online-tool 'BlueJeans' (powered by Verizon).

An advantage of this online-tool was the option to see video of all meeting attendees simultaneously to the shared screen of the presenter, and to use a chat function to answer comments or questions from the audience. Dr. Sara Stöber and Dr. Nina Donner (both from concentris) were also logged in, and took care of the latter while Liesbeth presented.

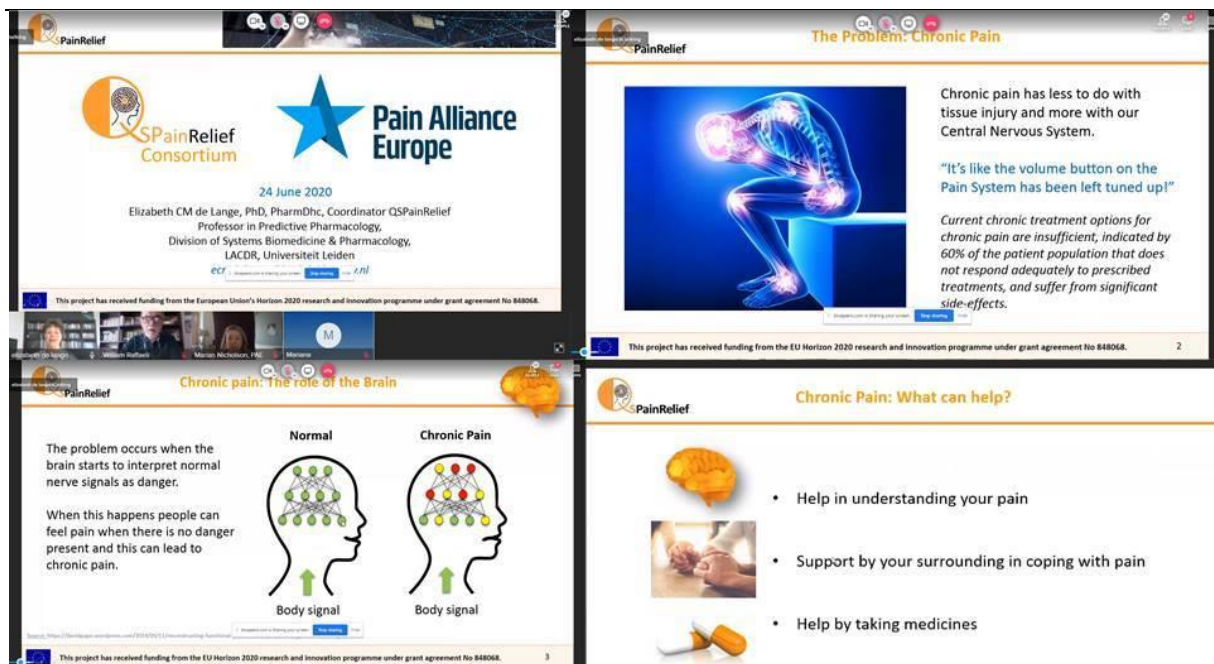


Figure 2. Arrangement of 4 exemplary screenshots taken during Liesbeth de Lange’s ppt presentation at Pain Alliance Europe’s (PAE) General Assembly Meeting on Wednesday, 24 June 2020.

2.3 Audience and Number of Attendees

The audience consisted of 23 layman and representatives of 19 national pain patient organisations from 13 different European countries. Being introduced to these patient organisations will also allow broader dissemination of results and targeted announcements of future patient events. Below is a list of the patient organisations that attended the event:

1. **BELGIUM** - FOCUS Fibromyalgie Belgique (focusfibromyalgie.be/)
2. **BULGARIA** - Federation Bulgarian Patients Forum (FBPF, fbpf.org/)
3. **EUROPE** - Active Citizenship Network (ACN, activecitizenship.net/)
4. **EUROPE** - European Network of Fibromyalgia Associations (ENFA, enfa-europe.eu/)
5. **FINLAND** - Suomen Kipu Ry (suomenkipu.fi/)
6. **GREECE** - Hellenic League Against Rheumatism (ELEANA, arthritis.org.gr/)
7. **IRELAND** - Chronic Pain Ireland (chronicpain.ie/)
8. **ITALY** - Fondazione ISAL (fondazioneisal.it/)
9. **MALTA** - No Pain Foundation (nopainfoundation.org/)
10. **NETHERLANDS** - De Maretak (demaretak.org/)
11. **NETHERLANDS** - Fibromyalgie en Samenleving (FES, fesinfo.nl/)
12. **NETHERLANDS** - International Painful Bladder Foundation (IPBF, painful-bladder.org/)
13. **PORTUGAL** - Associação De Doentes De Dor Crónica Dos Açores (*no website*)
14. **ROMANIA** - Myeloma Euronet Romania (MeR, myeloma.ro/)
15. **SPAIN** - Asociación española de pacientes contra el dolor (sinedolore.org)
16. **SPAIN** - Galician Rheumatological League (LRG, ligareumatotoxicagallega.es/)
17. **SWEDEN** - Swedish Rheumatism Association (reumatiker.se/)
18. **UNITED KINGDOM** - Pain UK (painuk.org/)
19. **UNITED KINGDOM** - Pelvic Pain Support Network (pelvicpain.org.uk/)

2.4 Feedback and Impact

The presentation was well-received by the audience.

We received multiple requests within the chat room of the online tool to share the original ppt presentation, prompting us to promise creating a professional webinar / video in high resolution, high audio quality, and with subtitles to make the talk barrier-free for audio-impaired people. During the next months, Liesbeth will record her talk using appropriate webinar software (such as 'Zoom'), and concentris will upload the video on YouTube and embed it on the project's website. In the meantime, the ppt presentation will be shared with interested patients and patient representatives via email upon request, and via the website's DOWNLOAD-page.

We also announced the upcoming production and distribution of the QSPainRelief info brochure (Deliverable D9.5, print and web version) by September 2020.

Another immediately measurable impact of the 1st patient & layman event was an increase in (a) the number of followers on the project's Twitter account from 29 to 35 ([@QSPainRelief](#)), and in (b) the number of followers on the project's LinkedIn account from 30 to 32 ([linkedin.com/company/qspainrelief/](https://www.linkedin.com/company/qspainrelief/)) as of 29/06/2020, as well as a peak in website visits and page views (measured via GDPR-conform Google Analytics). See Figure 3 for details.

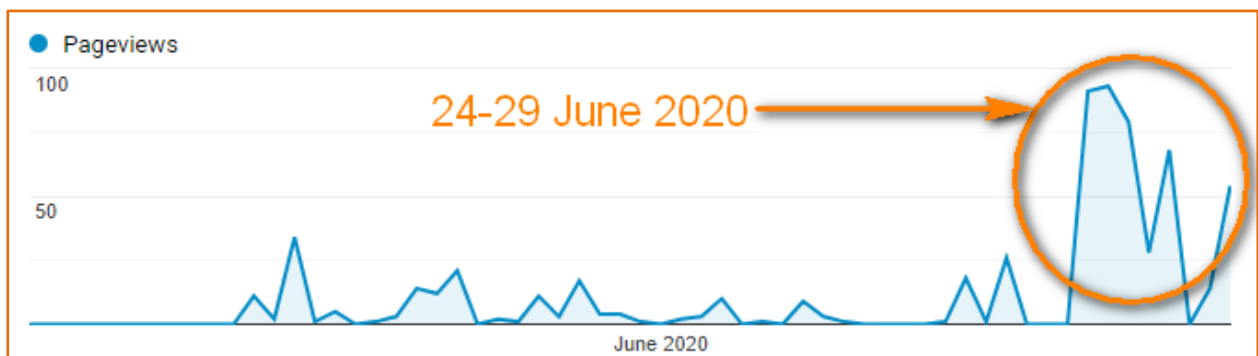


Figure 3. Increase in website page views immediately after the 1st patient & layman event.

3 Conclusion

In conclusion, the QSPainRelief team, including the IIB, is very satisfied with the interest, positive feedback, and overall outcome of the project's first patient & layman event. The event set the stage for the second patient & layman event at the end of the 2nd project year (due by month 24, meaning before December 2021), when first results and details about the clinical trials will be shared with the patient community.

4 Appendix

4.1 Agenda of PAE's Annual General Assembly (GA) Meeting



VIRTUAL PAE GENERAL ASSEMBLY

24TH JUNE, 2020

1 PM – BRUSSELS TIME

This is a closed meeting only for the PAE members. Each member organisation receives one link to be used from one computer only.

Please, note that this meeting will be recorded for the purpose of preparing the minutes of the meeting, therefore, by attending this meeting you give us your consent to record you.

AGENDA

1. Welcome and announcements (13h)
2. AGM 2020 approve the minutes of the AGM 2019 (*See appendix 1*)
3. Activity report 2019 for approval (*See appendix 2*)



4. **Balance/financial report 2019 for approval** *(See appendix 3)*

5. **Election of Board Members: a new board member Gemma Fernández and re-election of the board member Marian Nicholson** *(See appendix 4)*

6. **New member of PAE to be approved: De Maretak** *(See appendix 5)*

7. **Plans for 2021 for approval** *(See appendix 6)*

8. **Budget for 2021 for approval** *(See appendix 7)*

- 8b - **Membership fee 2021 for approval** *(See appendix 8)*

9. **Announcement of the results of PAE survey on Covid-19 and Chronic Pain**

10. **AOB**

11. **End (estimated at 14h30)**

There will follow a presentation that we believe will interest all members of PAE: Liesbeth De Lange from the QS Pain Relief project (14h30 -15h)