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Deliverable No. 2.2
Patient Board is formed

WP2

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Author(s)	Verena Schmeder, Marcos Mengual Hinojosa
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Checklist	**Y (Yes), N (No)**
1) The deliverable has been sent to all relevant partners for review (i. e. in the same task/WP):	Y
2) The deliverable has been endorsed by the WP lead and co-lead:	Y
3) Input from other WPs has been sought, if applicable: ***Please specify:***	N

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[1] **Type**: Use one of the following codes (in consistence with the Description of the Action):

R:	Document, report (excluding the periodic and final reports)
DATA:	data sets, microdata, etc.
DEC:	Websites, patent filings, videos, etc.
DEM:	Demonstrator, pilot, prototype
OTHER	

[2] **Dissemination level**: Use one of the following codes (in consistence with the Description of the Action)

PU:	Public, fully open, e. g. web
SEN:	Sensitive, limited under conditions of the Grant Agreement

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Executive Summary

Patient involvement is of central importance to the EURAS consortium and is at the core of the EURAS project. EURAS was initiated by the German patient organisation Syngap Elternhilfe e. V. (PA). Involving patients as equal partner enriches the researchers' work in manifold ways. Above all, it ensures that the needs of patients and their families are met in the project. In addition, involvement of PA gives the researchers of EURAS the unique opportunity to access patient data, which is crucial but also challenging for rare disease research.

The concept of a EURAS Patient Board (PB) was created to facilitate collaboration between the EURAS consortium and RASopathies patient organisations from different European countries. The members of the PB aim to multiply the project's outreach activities, converge the patients' feedback and translate the information that the English-speaking consortium shares with the public to national languages.

European patient organisations and groups for Syngap1, Cardio-facio-cutaneous Syndrome (CFC), Costello Syndrome and Noonan Syndrome were contacted by PA during the application phase of the EURAS project. Most of these organisations expressed their support for collaboration by Letters of Intent (LOIs) already at the time of grant application.

Upon the approval of the funding for the EURAS-project, further organisations were engaged and the nomination of the PB members was initiated. The General Assembly (GA) of the EURAS consortium approved the nomination of the PB members during the EURAS Kick-off meeting in July 2023.

The Inaugural PB Meeting was held as an online event in August 2023. Here, the project and the upcoming tasks were introduced to the PB members. This marks the starting point for the collaboration in the frame of the EURAS-project for the next 4 years.

1 Introduction

The herewith presented deliverable is part of Work Package 2 (WP2) and shall document the steps towards the formation of the EURAS PB. The D2.2 (Patient Board is formed) was fulfilled with the execution of the inaugural PB Meeting on August 22nd, 2023, where the PB of the EURAS project was established and initiated its work within the frame of WP2 and WP8.

The PB is coordinated and represented by the Patient Board Officer (PBO) and will help to create an international patient network that will be instrumental to reach, inform and recruit patients for the PATRAS registry. The PB will facilitate the direct contact and cooperation with families of patients and clinicians (PMU and OVGU), lead the recruitment of the patients for the surveys and help patients and families in case of questions and problems with questionnaires. This will be part of the upcoming tasks (Task 2.3). The PB will be also important to facilitate and multiply the activities within WP8, including project communication, networking and stakeholder outreach (Task 8.1 and 8.2).

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2 Description of Activities

2.1 Preparation Work for the Formation of the Patient Board

PA used their existing network of SYNGAP1 patient organisations (Syngap Global Network) as a basis for their recruitment of patient representatives for the PB. They established further contacts to other European patient organisations and patient support groups for CFC, Costello and Noonan Syndrome. These activities were started during the project application phase of the HORIZON Europe call and continued during the project preparation phase. During the application phase **most of the patient organisations had expressed their support** by sending LOIs.

At the beginning of the Project in June 2023, a PB Candidate Form was developed to be filled out by the potential candidates with the goal to clarify their background and to identify possible conflicts of interest. The PBO invited all European patient organisations and patient support groups to nominate 1 to 2 patient representatives for the EURAS PB (see 5 Deviations). Finally, a list of 37 nominated candidates from **24 organisations and groups from 12 countries** was sent to the WP leaders in advance. This list was presented for voting in a PB Candidates Report to the GA on 20/07/2023 during the EURAS Kick-off Meeting in Erlangen (Germany) (see Table 1, Figure 1, Table 2 and Table 3). **The GA approved all 37 candidates for the PB.** Afterwards the patient representatives were informed via email about their approval.

Country	CFC	Costello	Noonan	SYNGAP1
Austria				X
Switzerland			X	X
Germany	X		X	X
Spain	X	X	X	X
France	X	X	X	X
Italy				X
Netherlands/Belgium				X
Norway				X
Poland	X	X	X	X
Portugal				X
Sweden			X	X
United Kingdom		X	X	X

Table 1 – Overview Countries in the EURAS Patient Board

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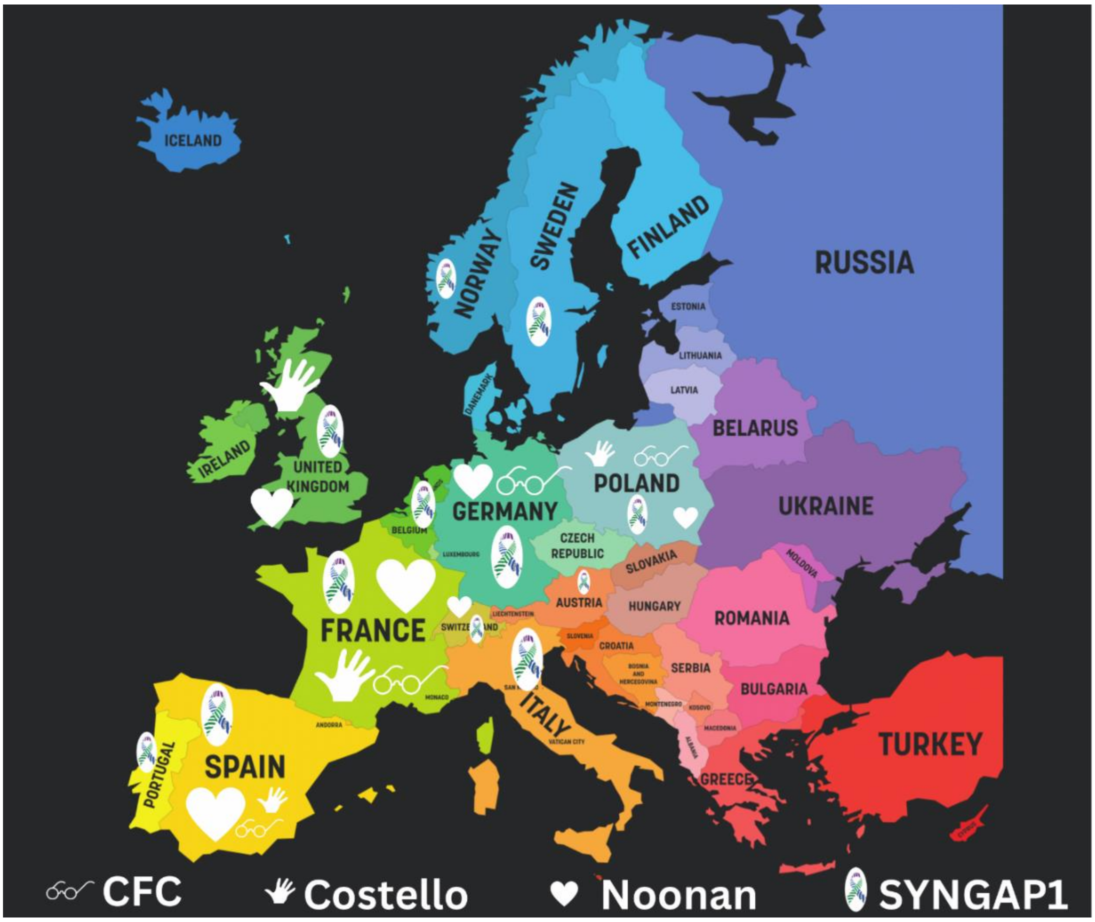

Figure 1 – Map of the EURAS Patient Board

Table of Patient Board Member Organisations – SYNGAP1

Country	Organisation
AT	Leon and friends e. V.
CH	SYNGAP1 Switzerland
DE	SYNGAP Elternhilfe e. V.
ES	SYNGAP1 España
FR	Overcome SYNGAP1
IT	SYNGAP1 Italia
NL	SRF EU
NO	SYNGAP1 Norway
PL	SYNGAP1 Poland
PT	SYNGAP1 Portugal
SE	Syngap1 Sweden
UK	SYNGAP1 UK
UK	SRF UK

Table 2 - List of Patient Board Member Organizations – SYNGAP1.

Note: The names of the representatives from each organisation are known to the consortium and will be published on the website of the EURAS project: https://euras-project.eu/.

Table of Patient Board Member Organisations – CFC, Costello, Noonan

Country	Organisation	CFC	Costello	Noonan
CH	Noonan Verein Schweiz			X
DE	Noonan Kinder Deutschland e.V.			X
FR	Association Noonan France			X
PL	Noonan Polska			X
UK	Noonan Syndrome Association, UK			X
SE	Svenska Noonanföreningen	X		X
ES	FEDERA España	X		X mainly
FR	AFS Costello & CFC	X	X	
DE	CFC Syndrom e.V.	X		
PL	CFC Polska	X		
PL	Costello Polska		X	
UK	ICSSG (Costello Support Group)		X	

Table 3 - List of Patient Board Organisations– CFC, Costello, Noonan

Note: The names of the representatives from each organisation are known to the consortium and will be published on the website of the EURAS project: https://euras-project.eu/.

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As a next step, the Patient Board Agreement (PBA) was drafted to regulate the cooperation of the PB members. Furthermore, the Non-Disclosure Agreement (NDA) was distributed to all PB members for signature. Finally, the collection of GDPR forms and materials for the website was started.
The date for the first PB meeting was determined in accordance with all PB members. So, the inaugural meeting was planned for Tuesday 22/08/2023 at 20:30 CET as an online meeting. The following agenda was sent with the invitation to all PB members (see Table 4).

Time	Topic
20:30	Welcome
20:45	Voting of the PB Agreement status & next steps
21:00	Short overview of the EURAS Consortium and all WPs
21:30	Tasks of patient representatives
22:00	Next Steps
22:30	Closure of the meeting

Table 4 - Agenda of Inaugural PB Meeting

2.2 Inaugural Patient Board Meeting (August 22nd, 2023)

2.2.1 Welcome of EURAS PB Members

The meeting started at 20:30 CET. The PBO welcomed all participants and invited them to briefly introduce themselves. In total 26/37 PB members attended the meeting representing 20/24 patient organisations and groups (see Figure 2). All participants have signed the NDA before the meeting and PBO pointed out the confidentiality of the prepared presentation.

The inaugural meeting of the EURAS Patient Board

This project has received funding from the European Union's Horizon Europe research and innovation program under Grant Agreement No. 101080580.

Figure 2 – MS Teams Meeting (screen shot with allowance of the participants)

2.2.2 Voting of the Patient Board Agreement

The draft version of the Patient Board Agreement (PBA) was sent to the patient organisations for review before the meeting. During the meeting, the PBA was presented and its rules were explained again for mutual understanding. The Participants were encouraged to ask questions and to provide feedback. There were no questions regarding the PBA.

Afterwards, the PBO requested the PB members to accept the PBA draft by a formal voting. The voting rules were explained, and the voting took place. **The PBA draft was accepted unanimously by all participants.** In the next step the PBA (draft) will be presented to the GA for final approval.

2.2.3 Presentation of the EURAS Consortium

An overview of the EURAS consortium was presented to the members of the PB and basic information about the WPs was provided. More detailed information was given about WP2 and WP8 regarding PB involvement.

In the subsequent discussion the representative of CFC Germany mentioned that the CFC/Costello group from Italy is willing to join the PB. First contact should be established by sending basic information about EURAS. The PBO will prepare an information sheet for them.

Furthermore, the Association Noonan France had a question regarding the translation process and the timelines of the different questionnaires. This question was responded with the presentation slide which shows the different questionnaire campaigns during the course of the project. The translations into different languages will be covered/managed by the patient representatives in their corresponding languages.

2.3 Upcoming Tasks of the Patient representatives

The different tasks of the PB members were outlined as follows: **Assisting in the questionnaire development and testing, translations and proofreading, patient recruiting, communication and dissemination activities.**

A question regarding participation in newsletters was raised and the PB invites interested members to participate in the creation of articles and written contributions. Everything related to the diseases and the work in the PB can be used for articles. The articles will be reviewed by the EURAS Communication Committee before publication.

A further question regarding the involvement of the ERN ITHACA was raised by a patient representative, who is a member of this ERN. The PB members in the meeting were informed that representatives of the ERNs **ITHACA and EpiCare will participate in the EURAS Advisory Board (EAB).** Additionally, a representative of EURORDIS will be involved in the EAB.

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2.4 Next Steps to Move the EURAS Project Forward

PBO asked for volunteers, willing to assist in the **development of the questionnaires**. Some of the participants expressed their interest in participation. The patient representatives were encouraged to forward the **press release** prepared by the EURAS-consortium and the link for the **pre-registration** of the PATRAS-registry to affected families and clinicians (www.rasopathies.eu). The PB will stay **open for more European patient groups and organisations to join.** Therefore, further contacts to other interested parties have been established and invitations have been issued. The newly nominated representatives will join the PB upon their approval by the GA of the EURAS consortium.

Next PB meeting will be arranged in approx. 2 to 3 months. The exact date will be coordinated with all PB members. For members of the PB, being unable to attend the event, the meeting minutes were prepared and will be distributed for information.

3 Results

The PB as a supportive body of the EURAS consortium was officially established during the inaugural PB meeting and is now fully operational. This is an essential step towards the planned international network of patient organisations and groups. The patient representatives will collaborate in the development of the PATRAS-questionnaires for the patient registry. Furthermore, they will support the recruitment activities by using their national contacts to support the multilingual outreach to different stakeholders as patients and clinicians and they will act as multiplicators with the goal to recruit patients for the registry. This will increase the impact of the project through patient outreach and engagement. These activities will belong to WP2 and WP8.
The full PB member list will be published and updated on the EURAS project website.

4 Conclusion

The high participation rate of the patient organisations proves the **outstanding motivation of patient parents** to support the work of the consortium by acting as representatives for the PB to directly contribute to WP2 and WP8.

The deep insight of patient parents into the disease as fulltime caregivers and their involvement in the project will enable **discovery of new aspects of the diseases**.

On top, there are best chances to reach or to exceed the assumed number of registered patients for both registry-parts as planned in the project proposal.

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5 Deviations

While the original plan was to include one patient representative per country per disease into the PB, it turned out to be more reasonable to include 1 to 2 representatives per country per disease as a team to fulfill the upcoming tasks, as some of these parents have a double or triple burden of caring for a child with special needs, a regular job and their activities as patient advocates. However, each team has one vote in the PB to ensure fair votings. This deviation was approved by the GA.

6 Annex

List of Abbreviations

CFC	Cardio-facio-cutaneous Syndrome
GA	General Assembly
LOI	Letter of Intent
NDA	Non-Disclosure Agreement
PA	Patient Association / Syngap Elternhilfe e.V.
PB	Patient Board
PBA	Patient Board Agreement
PBO	Patient Board Officer
EAB	EURAS Advisory Board
WP	Work Package

Table 5 – List of Abbreviations

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