

**Call:** HORIZON-HLTH-2022-DISEASE-06-two-stage  
**Topic:** HORIZON-HLTH-2022-DISEASE-06-04-two-stage  
**Funding Scheme:** HORIZON Research and Innovation Actions



# **Deliverable No. 8.1**

## **Project website with contents for publics, experts, and patients**

### **WP 8**

**Grant Agreement No.:** 101080580

**Project Title:** EUropean network for neurodevelopmental RASopathies (EURAS)

**Contractual Submission Date:** 30/09/2023

**Actual Submission Date:** 29/09/2023

**Responsible partner:** P15-EURICE

<b>Grant agreement no.</b>	101080580
<b>Project full title</b>	EUropean network for neurodevelopmental RASopathies

<b>Deliverable number</b>	8.1
<b>Deliverable title</b>	Project website with contents for publics, experts, and patients
<b>Type<sup>1</sup></b>	DEC
<b>Dissemination level<sup>2</sup></b>	Public
<b>Work package number</b>	8
<b>Work package leader</b>	Christina Eder
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<b>Keywords</b>	Project website, public website, visibility, communication, dissemination, information, outreach

EURAS has received funding from the European Union under the Horizon Europe Grant Agreement No. 101080580.

Views and opinions expressed are, however, those of the author(s) only and neither reflect those of the European Union nor European Health and Digital Executive Agency. Neither the European Union nor the European Health and Digital Executive Agency can be held responsible for them.

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

<sup>1</sup> **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

<sup>2</sup> **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

This deliverable shortly describes the initial set-up of the EURAS public project website with screenshots of the main pages attached in the annex.

### 1 Introduction

Providing information about EURAS' objectives and work as well as the results achieved over the course of the project's lifetime is of utmost importance to foster the project's success.

The EURAS public website is the project's predominant tool for communication about the project and, in the end, for disseminating results aiming at reaching the broader public as well as stakeholders and scientists in the field. The aim is to create continuous awareness of the project's activities. The public project website is part of WP8 "Innovation management & patient engagement".

### 2 Description of Activities

The EURAS website is directed at the general public, but also targets different stakeholder groups with an interest in the project, its activities, progress, outcomes and innovations. Such stakeholders include the scientific community, health care professionals and in particular clinicians, RASopathies and rare diseases patients as well as their families and caregivers, further interest groups such as governments/ministries of health, the medical industry and regulatory bodies.

The website offers a project introduction including key facts about EURAS. In addition, it offers background information about:

- the research, including the project's approach, objectives and work package structure,
- the consortium members,
- the patient organisations that are part of the patient board,
- information for patients on the project as well as on how to get involved via the European Patient Registry of RASopathies (PATRAS), which is one of EURAS' objectives,
- and news about the project activities, such as project-related events and news, as well as links to EURAS' social media channels.

The funding acknowledgement, imprint (including the mandatory disclaimer), privacy statement and entry point to the password protected intranet (Project Management Platform, see D1.1) are accessible at the bottom of the website on all pages.

The different sections are available in tabs in the main navigation panel with drop-down menus to subpages or in boxes on the home page or starting pages of the sections.

### 3 Results

The project website offers the following main features and information (provided as screenshots in the annex):

1. **Home:** Main page and entry point to the EURAS website providing the key facts and a short intro to the project
2. **Research:** Provides information about the project's **approach, objectives, work packages**, including a more detailed description of each work package, and a project timeline
3. **Team:** Provides information on the EURAS **partner** institutions and their teams – including an interactive visualization of the partners' locations, information on the EURAS Patient Board Network, where all patient organisations present themselves on an individual page; the EURAS Advisory Board page will be added soon
4. **For Patients:** Given that patients are central to the EURAS project, which was initiated by parents of RASopathies patients, the website offers one section that is dedicated to patients; here the project's approach and its objectives are summarized in more inclusive (i. e. laymen) terms, to make it more accessible also to a non-scientific community; in addition, the European Patient Registry of RASopathies (PATRAS) is introduced at the **"Get involved"** section with a link to the register
5. **News & Events:** Frequently updated section with news and events from the consortium and generated from subject-related content
6. **Contact:** Provides the main project contacts

The website went online on 19/07/2023. The sections described above have been added by the end of September. The website has been developed by a professional communications team at EURICE together with the coordinator (UKER) and has received feedback from the EURAS Communication Committee that includes patients' perspectives via partner PA (Syngap Elternhilfe e. V.). The website can be accessed via <https://euras-project.eu/>.

### 4 Conclusion

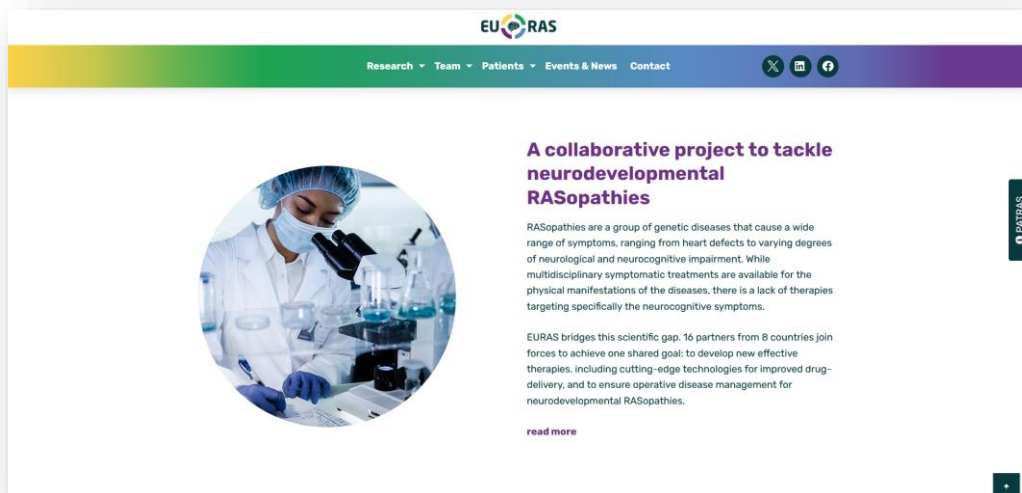
The website as well as the social media accounts provide information to the interested user and are in line with the project's corporate identity. The website's set-up ensures that the site is appealing, efficient and intuitive. Since the development of the website is a continuous task, the website as presented in this deliverable must be considered as a 'snapshot'. Content will be regularly updated. Additional information and subpages will be introduced in the course of the project.

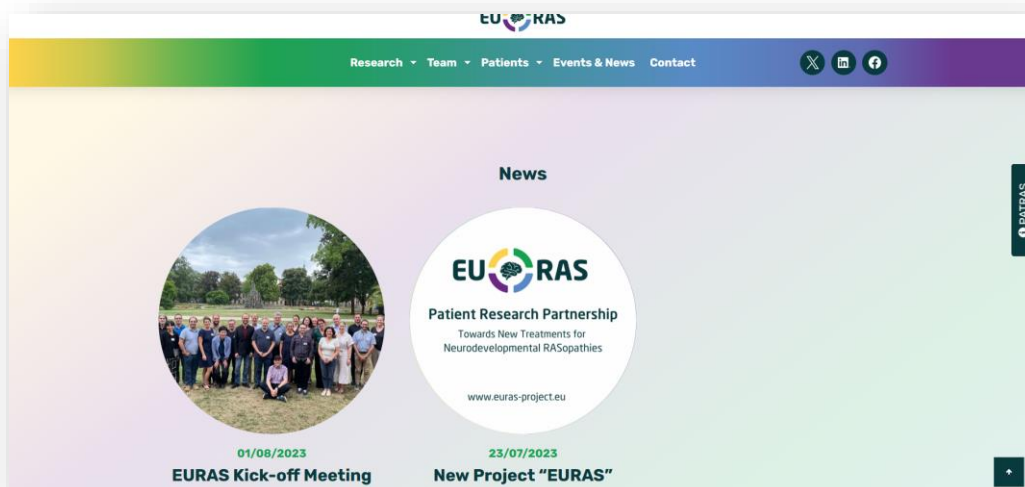
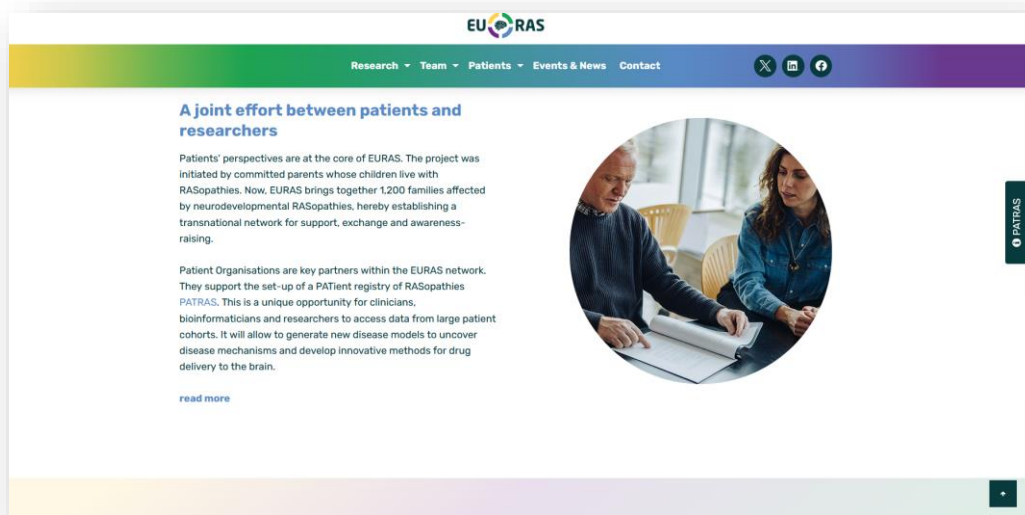
### 6 References

<https://euras-project.eu/>

## 7 Annex

### (1) Home





(2) Research (Sub-Section: Work Packages)

The screenshot shows the EU RAS website interface. At the top, there is a navigation menu with options: Research, Team, Patients, Events & News, and Contact. Below the menu, there is a dropdown menu with options: Approach, Objectives, Work Packages, and Timeline. The main content area contains text about the project's approach and objectives, followed by a call to action: "For more information, please click on the graphic below". Below this is a flowchart illustrating the project structure:

- WP1** (Project management & scientific coordination) is shown as a vertical bar on the left.
- WP2** (PATRAS: advanced bioinformatics-assisted implementation and exploitation) is a green box at the top left.
- WP3** (Generation and validation of disease models) is a blue box below WP2.
- WP4** (Analysis of disease models to identify and evaluate "disease signatures") is a green box at the top right.
- WP5** (Phenotype-based drug screening and ASO development) is a blue box below WP3.
- WP6** (New technologies for brain delivery of statins and ASOs) is a blue box below WP5.
- WP7** (Evaluation of treatment success) is a green box at the bottom, receiving input from WP3, WP5, and WP6.
- WP8** (Innovation management & patient engagement) is shown as a vertical bar on the right.

The screenshot shows a detailed view of Work Package 8: Innovation management & patient engagement. The title is "Work Package 8: Innovation management & patient engagement". The text describes the role of WP8: "Work Package 8 is responsible for "Innovation management & patient engagement". Innovation management will follow a multidimensional, integrated and impact-oriented approach. It will ensure consistent communication and dissemination, optimal visibility and a wide outreach to stakeholders. Strategic planning and implementation of exploitation will safeguard that the high-quality results are captured, assessed and used. A proper IP management strategy will lay the foundation for further exploitation and sustainability activities considering background knowledge of beneficiaries and newly created results."

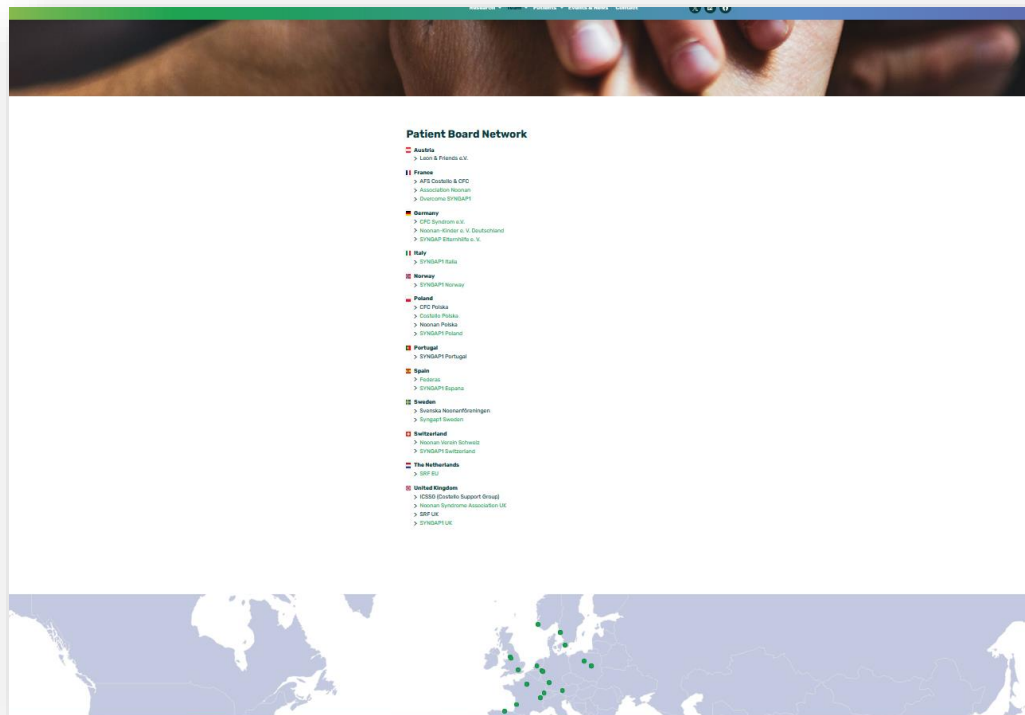
Below the text, there is a list of partners:

- > EURICE – European Research And Project Office GmbH
- > Syngap Elternhilfe e. V.
- > Universitätsklinikum Erlangen

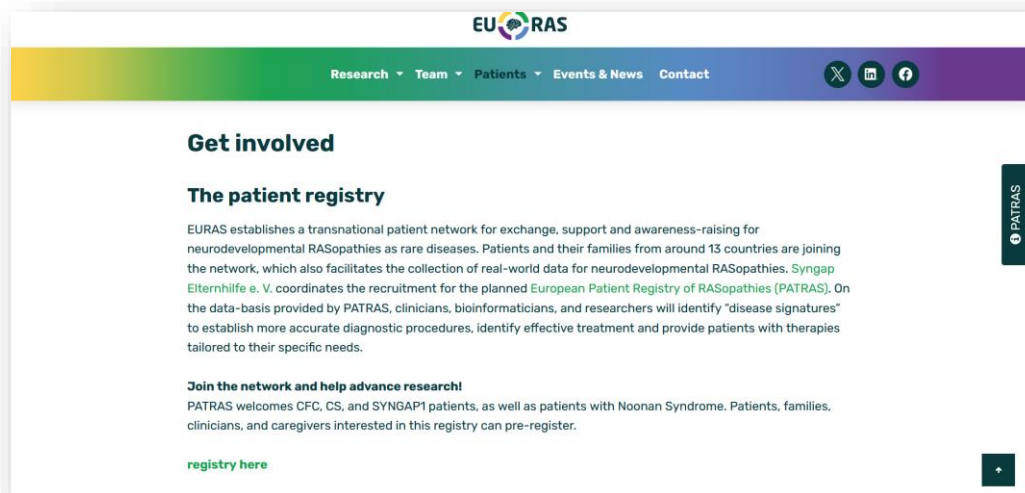
The background of this screenshot shows a partial view of the flowchart from the previous screenshot, with WP3, WP5, and WP6 visible.



### (3) Partners (Sub-Sections: Partners & Network)



### (3) Patients (Sub-section: Get Involved)



### (4) Events & News

