



INTERNATIONAL WORKSHOP ON RASOPATHIES (IWRAS26)

Strengthening Translational Collaboration between Research, Clinical
Practice and Patient Communities

Rectorate of the University of Málaga, Spain

September 17 - 18, 2026

WELCOME MESSAGE

Dear Friends, Colleagues, and Families,

A warm welcome to the **International Workshop on RASopathies: Strengthening Translational Collaboration between Research, Clinical Practice and Patient Communities (IWRAS26)**.

RASopathies are complex conditions that affect individuals and their families far beyond the medical symptoms. Finding answers and developing effective treatments is a journey that requires all of us working together. That is why this workshop is so important to us: it brings together under one roof the scientists pushing the boundaries of research, the clinicians caring for patients every day, and the families who live with these conditions and inspire our work.

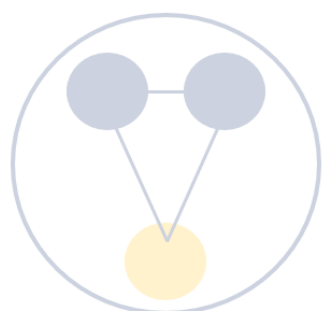
Over the next few days, we will discuss the latest scientific breakthroughs, from genetic discoveries to new therapeutic approaches. But beyond the data, what we truly want is to connect these different worlds. We want to ensure that what happens in the lab translates directly into better care in the clinic and real support at home.

Thank you so much for being here in Malaga and for sharing your knowledge, your time, and your stories. Whether you are presenting a study, sharing clinical expertise, or bringing the invaluable perspective of a parent, your presence makes this collaboration possible.

We hope you enjoy the workshop and the meaningful conversations ahead.

With our warmest regards,

THE IWRAS26 ORGANIZING COMMITTEE



SCIENTIFIC PROGRAM

Day 1: Thursday, September 17, 2026

SESSION & PRESENTATION DETAILS

09:00 – 09:15	Opening Session Welcome remarks by Local and Institutional Authorities.
09:15 – 09:35	Inaugural Conference Bioinformatics: Essential support for rare disease diagnosis, clinical assays and treatment. Dr. Juan A. G. Ranea (IBIMA-Rare, UMA, Spain)
09:35 – 11:15	Session 1: Patient and Caregiver Perspective <i>Chair: Dr. Marina Calleja Reina (UMA, Spain)</i> 09:35 – 09:55 EURAS Approach: Advancing RASopathies research. Marcos Mengual Hinojosa (Father and patient advocate EURAS, EU) 09:55 – 10:15 SYNGAP1 Advocacy: Challenges, progress and impact. Dr. Jaime Aranda Durán (Asociación SYNGAP1 España) 10:15 – 10:35 Living with Rare Diseases: Challenges faced by families. Dr. Jesús M. Bonill Jiménez (UMA, Spain) 10:35 – 10:55 Overview of computational methods for drug repurposing. Dr. Florencio Pazos (CNB-CSIC, Spain) 10:55 – 11:15 Managing Regression: The families' perspective. Dra. Encarnación Postigo Pinazo (UMA, Spain)

11:15 – 11:45

Coffee Break & Networking

11:45 – 13:30	Round Table 1: Needs and Advances in Patient Care An open panel discussion with speakers, clinicians, researchers, and families addressing educational hurdles, psychosocial support, and standardizing multidisciplinary care pathways.
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13:30 – 15:00

Lunch Break

SESSION & PRESENTATION DETAILS

15:00 – 17:30

Session 2: Research & Future Prospects

Chair: Dr. Fernando Cabrera Bueno (HUVVM, Spain)

15:00 – 15:20 | New Tech: Improving quality of life for rare diseases.

Lorenz Kiwull, M.D. (PMU, Salzburg, Austria)

15:20 – 15:40 | SYNGAP1 Haploinsufficiency: Developmental consequences.

Dr. Maria Isabel Carreño Muñoz (Montreal, Canada)

15:40 – 16:00 | UNICAS-IMPACT: National pediatric network for personalized medicine.

MsC. Helena Rodríguez González (HSJD, Spain)

16:00 – 16:20 | RASopathies in neurology: from intracellular signaling to epileptogenesis.

Dr. Jorge Romero Godoy (Hospital Virgen de la Victoria, Spain)

16:20 – 16:40 | Costello Syndrome: Modeling and treating with CRISPR iPSCs.

MsC. Joana Jeremias (IBB, Portugal)

16:40 – 17:30

Round Table 2: Future Perspectives on RASopathies Research

Strategic discussion focused on multi-omics integration, funding frameworks, international registries, and cooperative clinical trial design.

Day 2: Friday, September 18, 2026

SESSION & PRESENTATION DETAILS

09:00 – 09:45

Keynote Lecture

A gene therapy approach to correcting SYNGAP1-related disorder.

Dr. Boaz P. Levi. (Allen Institute, Seattle, U.S.A.)

09:45 – 11:05

Session 3: Translational Activities

Chair: Dr. Raquel Yahyaoui Macías (IBIMA-Rare, Spain)

09:45 – 10:05 | Epilepsy Management: Optimal targeted therapies for SYNGAP1.

Kirsten Eschermann, M.D. (PMU, Salzburg, Austria)

10:05 – 10:25 | AI in Diagnosis: Accurate phenotyping approaches in RASopathies.

Dr. María Elena Rojano Rivera (UMA, Spain)

10:25 – 10:45 | Computational Phenotyping: Preventing systematic data pitfalls in rare cohorts.

Dr. James Richard Perkins (UMA, Spain)

10:45 – 11:05 | Artificial Intelligence: Future perspectives and clinical decision support systems.

Julián Isla (Father and patient advocate, Microsoft / Fundación 29)

11:05 – 11:30

Coffee Break

11:30 – 13:00 Round Table 3: Translational activities for RASopathies

Discussion on present and future of translational activities for RASopathies and their associated difficulties.

13:00 – 13:30 Conclusions and Workshop Closure

Final remarks, next milestones and action points for international registries.

Marcos Mengual Hinojosa (Father and patient advocate EURAS, EU)

Interpreter for the Workshop: Dr Laura Parrilla Gómez (UPO, Spain)

SCIENTIFIC AND ORGANIZING COMMITTEES

Dr. Encarnación Postigo Pinazo

Dr. Francisca Sánchez Jiménez

Dr. Juan A.G. Ranea

Dr. María Elena Rojano Rivera

Dr. Manuel Bernal Muñoz

Dr. Raquel Yahyaoui Macías

Dr. James Richard Perkins

Dr. Pedro Seoane Zonjic

SPONSORS & COLLABORATORS

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- IBIMA Plataforma BIONAND
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- Ministerio de Ciencia e Innovación, Gobierno de España
- EURAS Network



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