

European Meeting of Patient Organizations

26 , 27 October- Madrid

PROGRAM

WORKSHOP ON DISCRIMINATION. MADRID 26 OCTOBER

DATE: Monday October 26th

LOCATION: Madrid

TIME: 3:00 PM

AGENDA

3:00 PM – 4:00 PM: Welcome and Introductions

- Mr. Jesús Celada: Ambassador-at-Large for the Convention on the Rights of Persons with Disabilities
- Ms. Virginia: Secretary General of the ONCE Foundation
- Erin Pritchard: Senior Lecturer in Disability Studies ,activist and expert in skeletal dysplasias.
- Susana Noval Iruretagoyena. ERN BOND ePAG, European Reference Networks presentation.
- Juan Carrion, President of FEDER (Spanish federation rarer diseases)
- **Representative** of the European Disability Forum
- Questions and Answers

Working Groups

4:00 PM – 7:00PM with Break (5:00-5:20 PM)

- **Goal 1:** To identify discrimination scenarios across different European countries and establish intervention models.
- **Goal 2:** To create a European advisory committee to support organizations.

7:00 PM – 7:30 PM: Presentation of the SDA (Skeletal Dysplasia Alliance)

- Session with all organizations and authorities and press.

9:00 PM: Dinner

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Inscrita en el registro de Fundaciones Docentes y Culturales del Principado de Asturias, CIF G33863515, núm. 132, t. 1, folio 33, sección 1ª

**CONFERENCE: RIGHTS AND NON-DISCRIMINATION OF PEOPLE WITH SKELETAL
DISPLASIAS.**

MADRID 27 OCTOBER

DATE: October 27th

LOCATION: Puerta de Toledo – Salón de Grados –Carlos III University - Madrid

ORGANIZERS: ALPE Achondroplasia Foundation and the Gregorio Peces-Barba Institute of Human Rights, Carlos III University of Madrid

PROGRAM

09:30 AM – 10:00 AM: Institutional Opening

- **Representative** of the ALPE Foundation
- Ms. María del Carmen Barranco Avilés: Director of the Gregorio Peces-Barba Institute of Human Rights – Carlos III University of Madrid
- Mr. Jesús Martín Blanco: Director General for the Rights of Persons with Disabilities (Government of Spain) and Director of the Royal Board on Disability

10:00 AM – 12:00 PM: PANEL 1

"People with Skeletal Dysplasias and Human Rights: Discrimination and Social Stigma"

- **Moderator and Presenter:** Mr. Rafael Fernando de Asís Roig, Professor of Philosophy of Law at Carlos III University of Madrid
- Mr. Saulo Fernández Arregui: Professor of Social and Organizational Psychology, National University of Distance Education (UNED)
- Ms. María Carmen Barranco: Associate Professor of Philosophy of Law at Carlos III University of Madrid (UC3M)
- Mr. Felipe Orviz Orviz: ALPE Achondroplasia Foundation

12:00 PM – 12:30 PM: COFFEE BREAK

12:30 PM – 02:00 PM: PANEL 2

"Experiences and Testimonials"

- **Moderator:** Patricia Cuenca
- **Participants:** Representatives of Skeletal Dysplasia associations from Spain and the European Union

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02:00 PM – 03:30 PM: LUNCH

03:30 PM – 05:00 PM: PANEL 3

"Legal and Intervention Tools: Responses to Discrimination"

- **Moderator:** Felipe Orviz Orviz, ALPE Achondroplasia Foundation
- Ms. Elena Pertusa Rodríguez: Prosecutor assigned to the Prosecutor's Office for Hate Crimes and Discrimination, State Attorney General's Office
- Mr. Gregorio Saravia Méndez: Delegate of the National CERMI for Human Rights and the UN Convention on Disability
- Ms. Encarnación Carmona Cuenca: Professor of Constitutional Law at the University of Alcalá

05:00 PM – 05:30 PM: CONCLUSIONS AND CLOSING REMARKS

- Ms. Virginia Carcedo Illera: Secretary General of the ONCE Foundation
- **Representative** of the Rectorate of Carlos III University of Madrid
- Mr. Jesús Celada: Ambassador-at-Large for the Convention on the Rights of Persons with Disabilities

FREE TIME

9:00 PM DINNER