

PROGRAM

INTERNATIONAL  
DUCHENNE  
CONGRESS  
PARENT PROJECT  
ESPAÑA

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22.23.24  
MAY 2026

Endorsed by:



# FRIDAY, MAY 22

(broadcast in Spanish only)

## 12:00- 14:00H RECEPTION AND BADGE PICK-UP

**Children's playroom and entertainment service:** It will be available during all sessions, starting 15 minutes before and ending 15 minutes after the start of the tables.

## 14:00-15.15H GETTING TO KNOW EACH OTHER. DMD/BMD FAMILIES. WELCOME WORKSHOP

Welcome: **M<sup>a</sup> Angeles Alonso**, Board of Directors, Duchenne Parent Project Spain.

Moderator: Duchenne Parent Project Spain  
Psychological Support Service: **Mr. David Díaz-Pinto Asensio, Ms. Paula Trabado, Ms. Ángela Moral de Pablos.**

## 15:30 - 16:00H WELCOME AND INSTITUTIONAL OPENING

**Ms. Silvia Ávila.** President of Duchenne Parent Project Spain.

**Dr. César Hernández García.** Director General of the Common Portfolio of NHS Services and Pharmacy - Ministry of Health.

**Ms. Esther Sabando.** Director of Institutional Relations and Patient Advocacy at DPPE.

**Dr. Celia García Menéndez.** Director General for Humanization, Care and Patient Safety - Community of Madrid

## 16:00-18:00H ROUND TABLE: FAMILIES-CLINICIANS-PATIENTS

During this round table, topics related to standards of care will be discussed.

Moderator: **Dr. Marisol Montolio.** Director of the Research Department and the Technology Department of Duchenne Parent Project Spain

**Dr. Francina Munell.** Hospital Vall d'Hebrón (Barcelona): "Newly diagnosed"

**Dr. David Gómez.** Hospital Vall d'Hebrón (Barcelona) "Cognitive involvement in DMD"

**Dr. Marcos Madruga.** Neurolinkia (Seville): "Corticosteroids and side effects"

**Dr. Carlos Ortez.** Hospital Sant Joan de Déu (Barcelona): "DMD/BMD transition protocol"

**Dr. Andrés Nascimento.** Hospital Sant Joan de Déu (Barcelona): "Multidisciplinary clinics"

**Dr. Miguel Ángel Fernández.** Hospital Universitario La Paz (Madrid): "Diferentes fenotipos en la DMD"

**Dr. Sergi Cesar.** Hospital Sant Joan de Déu (Barcelona): "Cardiac involvement in DMD, BMD and carriers"

**Dr. Julita Medina.** Hospital Sant Joan de Déu (Barcelona): "ehabilitation in DMD and BMD patients"

**Dr. Carlos Carrera.** Hospital Virgen del Rocío (Seville): "Pediatric and adult respiratory management in DMD and BMD"

**Dr. Juan Restrepo.** Hospital Vall d'Hebrón (Barcelona) "The Duchenne and Becker adult"



# SATURDAY, MAY 23

## 8:30- 8:45H WELCOME AND OPENING OF THE SCIENTIFIC DAY

**Ms. Silvia Ávila Ramírez.** President, Duchenne Parent Project Spain.

## 8:45-9:00H DUCHENNE PARENT PROJECT SPAIN SCIENTIFIC STRATEGY: A GLOBAL VISION FOR THE CURE

**Dr. Marisol Montolio.** Director of the Research Department and the Technology Department of Duchenne Parent Project Spain.

## 9:00-10:00H PRECLINICAL STUDIES FUNDED BY DPPE

During this session, we will discuss preclinical research and how to optimize this important phase of drug development to achieve greater success and generate more clinical trials in the future.

- › BIND Screener (BIND-S): rapid detection of cognitive, behavioral, and emotional difficulties in Duchenne. **Dr. Rubén Miranda** (Complutense University of Madrid)
- › bioND: Systemic in vivo cellular reprogramming restores full-length dystrophin in DMD. **Dr. Jesús Beltrán** (DNAMic)
- › INNO-CARRIER: The monitoring study in carrier and non-carrier women with relatives affected by DMD. **Sari Gómez**, (Duchenne Parent Project Spain)
- › Deciphering the challenges of cardiac muscle in Duchenne muscular dystrophy. **Dr. Icíá Santos**, (Health Research Institute of Santiago)

## 10:00-13:00H / 14:30 A 17:00H PARALLEL SESSION: POSTERS

## 10:00-13:00H PARALLEL SESSION: SCIENCE WORKSHOP

## 10:00-10:10H THERAPEUTIC STRATEGIES: CURRENT LANDSCAPE. WHAT IS A CLINICAL TRIAL?

In this session, the strategy carried out by Duchenne Parent Project Spain to reach DMD/BMD clinical trials more quickly will be explained: Patient Registry, SARA Program.

**Dr. Marisol Montolio.** Director of the Research Department and the Technology Department of Duchenne Parent Project Spain

## 10:10-11:00H CLINICAL TRIALS: Gene therapy

This block dives into the most ambitious field today: the ability to combat the disease at its root.

SGT-003: Solid's Next-Generation Gene Therapy Candidate for Duchenne Muscular Dystrophy. **Patrick Gonzalez**, Solid

**Arnaud Valent**, Genethon

Phase 3 Study SHIPPING: update **Dr. Maitea Guridi**, Roche

## 11:00-11:30H COFFEE BREAK

Participants may head to the networking area to meet exhibitors, speak with experts, and chat with Duchenne/Becker families.

### 11:30-13:00H PARALLEL SESSION: MUTUAL SUPPORT GROUPS (MSGs) AIMED AT:

- > Pre-adolescents
- > Adolescents
- > Adults affected by Duchenne or Becker muscular dystrophy

### 11:30-13:00H CLINICAL TRIALS: EXON SKIPPING

Exon skipping using antisense oligonucleotides is one of the most developed genetic strategies for Duchenne.

- > “An Update on Sarepta Therapeutics’ Exon-Skipping Therapies” **Nicole LaMarca**, Sarepta
- > Topline Results from Phase 1/2 DELIVER Trial of zeleciment rostudirsen in Exon 51 Skip Amenable DMD. **Jordan Messer**, Dyne
- > Update on Entrada’s Clinical Programs. **Dr.Gómez** Hospital Vall d’Hebron
- > BMN 351 en Duchenne Muscular Dystrophy (DMD). **Dr.Angel Ayuga**, Biomarin
- > An industry update from Avidity Biosciences: Delpacibart-zotadirsen (AOC1044). **Carmen Castrillo**, Avidity

### 13:00-14:30H LUNCH: SOCIAL INTERACTION

### 14: 30-14:40H RESEARCH: WHERE WE ARE AND WHERE WE ARE GOING

Dr. Marisol Montolio. Director of the Research Department and the Technology Department of Duchenne Parent Project Spain

### 14: 40-15:40H BEYOND DYSTROPHIN: INNOVATION IN MUSCLE, BONE, AND INFLAMMATION

Managing bone and muscle health and the inflammatory response is crucial to preserve function and improve long-term quality of life.

**Dr. Maitea Gurudi.**

- > Edgewise Therapeutics: Building Community and Advancing Science in Becker Muscular Dystrophy. **Katherine Krieger**, Edgewise.
- > Givinostat study in non-ambulant patients: **Paolo Tornese**, Italfarmaco SpA
- > Satellos: “From regeneration to function: advances in muscle repair with SAT-3247” **Dr. Gómez**, Hospital Vall d’Hebrón.
- > Phase 2 SHIELD DMD study: current program update, **Dr. Maitea Gurudi**, Roche.

### 15:40-16:20H NEW HORIZONS IN SPAIN: GUIDE TO TREATMENTS CURRENTLY APPROVED FOR DUCHENNE

Duchenne muscular dystrophy (DMD) is at a historic turning point. After years of intensive research, the therapeutic landscape in Spain is undergoing an unprecedented transformation. In this block, we will explore the current situation in our country.

- > Givinostat in Spain, **Laura García Ortí**, Italfarmaco España
- > Agamree (vamorolona): long-term data update, **Marianne Berrens Santhera**

### 16:20-16:50H COFFEE BREAK

Time to rest and head to the networking area to meet exhibitors, speak with experts, and chat with Duchenne and Becker families.

**SATURDAY AFTERNOON ARM  
SUPPORT DEMONSTRATION****16: 50-17:45H CARRIERS: “The Double Burden: Psychosocial Approach and Genetic Counseling Strategies in Women Carriers of DMD.”**

This session focuses on the role of the woman carrier, often invisible within the disease ecosystem. It will explore the “double burden” they face: emotional management alongside their own physical health risk and the psychological impact of a genetic diagnosis. We will address the importance of up-to-date genetic counseling that empowers reproductive decision-making.

Participants in this block will include: **Dr. Marisol Montolio, Paula Trabado**, DPPE Psychologist, **Begoña Martín Bielsa** (ASEM) and **M<sup>a</sup> Ángeles Alonso** (DPPE)

**17:45-18:15H BEST SCIENTIFIC POSTER AWARD 2026**

Throughout the congress, attendees will be able to explore the scientific poster area, a meeting point where researchers, students, and professionals share their latest findings. Your opinion matters: visit the exhibition, discover emerging talent, and vote for the best work to decide the congress award.

**18:30-19:00H OSLO ROOM: TECHNOLOGY: ESSENTIAL SUPPORT FOR DUCHENNE AND BECKER MUSCULAR DYSTROPHIES**

During this session, we will talk about implementing different devices that can help ease the course of the disease. We also expect an exchange of knowledge on the use of digital outcomes that will be used in Duchenne research, drug development, and daily management.

This session will be led by members of the DPPE Technology Department: **Dr. Marisol Montolio, Laura Vilanova, Dr. Sebastian Idelsohn, MSc. David Díaz-Pinto, MSc. Aaron Vilalta and MSc. Raquel Ávalos.**

**19:00-20:00H OSLO ROOM: PRACTICAL WORKSHOP ON EMERGENCIES IN DUCHENNE AND BECKER**

Workshop focused on managing emergency situations in patients with DMD/BMD, clearly and practically addressing responses to fractures, choking, and other common incidents, providing useful tools for a fast and safe response.

**Dr. David Andina.** Emergency pediatrician and co-director of first aid courses.

**21:30H GALA DINNER**

This is the last opportunity to share experiences with families, doctors, and researchers.

Welcome: **M<sup>a</sup> Paz Herminda**, Board of Directors, Duchenne Parent Project Spain.

# SUNDAY, MAY 24

(broadcast in Spanish only)

## 9:25- 9:30H WELCOME AND FAMILY SUPPORT DAY

**Ms. Carmen María Ventura García.** Board of Directors, Duchenne Parent Project Spain - Family Support.

## 9:30-10:00H STATUS OF THE ELA LAW IN DUCHENNE AND BECKER

We will assess the implementation status in each autonomous community, identifying territorial differences in access to resources.

**Ms. Esther Sabando.** Director of Institutional Relations and Patient Advocacy.

## 10:00-10:30H SOCIAL PROTECTION AND LEGAL FRAMEWORK: CUME AS A PILLAR OF COMPREHENSIVE CARE

A session dedicated to explaining the right to reduced working hours to care for minors with serious illness. The current regulatory framework, the granting criteria used by collaborating mutual insurance providers, and the importance of this benefit for ensuring socioeconomic stability and quality of care within the family environment of those affected by DMD/BMD will be analyzed.

**Dr. Álvaro Lavandeira Hermoso.** Lawyer, Doctor in Health and Pharmaceutical Law

## 10:30-11:00H PHYSIOTHERAPY AND DMD: KEY STRATEGIES FOR LONG-TERM FUNCTIONAL PRESERVATION

Essential tools to optimize patient mobility and comfort through a multidisciplinary approach.

**Ms. Obdulia Moya Arcos.** Specialist physiotherapist, Neuromuscular Unit, SJD.

## 11:00-11:30H EDUCATIONAL ENVIRONMENT IN DUCHENNE AND BECKER MUSCULAR DYSTROPHY

The main aspects to consider in the educational environment to improve the quality of life of people with DMD and BMD will be discussed.

**Mr. David Díaz-Pinto.** Psychologist Duchenne Parent Project Spain

## 11:30-12:00H SEXUALITY AND SEX EDUCATION IN THE CONTEXT OF FUNCTIONAL DIVERSITY IN DMD & BMD.

Sexuality as an essential dimension from childhood onward. Importance of early sex education. Specific needs, educational guidelines, and support to foster affective-sexual development, autonomy, and quality of life.

**Ms. Paula Trabado.** Psychologist, Duchenne Parent Project Spain

## 12:00H CONCLUSIONS AND CLOSING

**Ms. Silvia Ávila Ramírez.** President Duchenne Parent Project Spain

## 12:00-13:00H ANNUAL GENERAL ASSEMBLY FOR DUCHENNE PARENT PROJECT SPAIN MEMBERS ONLY

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