

2nd INTERNATIONAL CONGRESS
&
1st INTERNATIONAL CONSENSUS REVISION
on Beckwith-Wiedemann Spectrum (BWSp)

ALL IN ONE



Sotto l'alto patrocinio
del Parlamento europeo

IMPORTANT INFORMATION
& PROGRAM

Segreteria organizzativa

CERVIA ITALY
HOTEL DANTE



28 MAY
02 JUNE 2026

SCIENTIFIC COMMITTEE (in alfabetic order)

Alessandro Mussa
Andrea Riccio
Deborah Mackay
Eamonn Maher
Frédéric Brioude
Jennifer Kalish
Thomas Eggermann

ORGANIZING SECRETARIAT:

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**Sotto l'alto patrocinio
del Parlamento europeo**

**CERVIA ITALY
HOTEL DANTE**

Organizing Secretariat



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Rationale of the 2nd International Congress on BWSp

**“All in one” is not just a title, but a way of being:
together, in the same place, with a single goal.
Taking care of children with BWSp by building authentic,
solid and shared relationships for the benefit of everyone.**

From birth, our emotional, psychological and social well-being is shaped by the way we relate to others. The quality of the relationships we build has a decisive impact on our ability to face challenges, collaborate, grow and generate shared value. In this sense, collaboration and trust represent the essential foundations of any healthy, effective and lasting relationship capable of benefiting all stakeholders involved.

Positive relationships are never accidental, but depend largely on how each of us chooses to engage: through listening, openness, mutual respect and a willingness to build together. Positive relationships foster effective communication, reduce conflict and misunderstandings, and create an atmosphere of safety and sharing that allows even the most complex pathways to be addressed with greater awareness and serenity.

In the world of BWSp, these principles take on even greater importance.

Children affected by BWSp require complex care, characterised by strong multidisciplinary and often by significant and prolonged hospitalisation. In this context, **the child’s well-being does not depend solely on the quality of clinical care, but also on the quality of the relationships established around them.**

It is therefore essential that physicians, specialists, healthcare professionals and families are able to build a positive, collaborative relationship based on mutual trust. **Only through a genuine alliance is it possible to ensure that the child is not treated as a collection of protocols or diagnoses, but recognised in their entirety, as a person at the centre of a shared care system.** An informed family that feels listened to and trusts the specialists caring for their child is inevitably a more collaborative, aware and active participant in the care pathway.

In this scenario, patient associations play a key and irreplaceable role. They represent a fundamental link between families, professionals and institutions, facilitating dialogue, mutual understanding and continuity of care. Associations not only support and guide families, but also help build a network of trust, disseminate accurate information and promote a culture of collaboration that extends far beyond the single clinical setting.

Meeting in person: for doctors and specialists, seeing the children they follow outside a clinical setting means going beyond clinical data, records and tests, strengthening professional motivation and the deeper meaning of their scientific and human commitment.

For families, meeting in person the many experts who work with science and conscience on BWSp and their children allows them to understand the complexity and quality of the work being done, further strengthening trust in the multidisciplinary team accompanying them along the care pathway.

An International Congress therefore represents a rare but fundamental opportunity to foster these encounters, consolidate relationships and create an authentic space for dialogue and sharing. It is a place where expertise, experiences and lived realities meet, and where multidisciplinary and international dialogue becomes a concrete tool to improve care for children and support for families.

The 2nd International BWSp Congress thus represents a crucial moment to reaffirm that the quality of relationships is an integral part of care.

Investing in collaboration, trust and direct encounters means investing in the well-being of children, in family support and in the growth of an increasingly cohesive, aware and common-good-oriented scientific and human community.

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INTERNATIONAL CONSENSUS 1st REVISION PROGRAM

Access reserved only for professionals and PAOs
already involved in the works

Thursday, 28 May 2026

- H. 13.00 Welcome lunch
- H. 14.30 Plenary Session: welcome, introduction, methodology, preparatory works
- H. 15.30 WG1-WG2-WG3: revision of the first recommendations, overview of the literature, definition of contents
- H. 19.30 Dinner

Friday, 29 May 2026

- H. 09.00 Plenary Session: restitution of WG contents
- H. 11.30 WG1-WG2-WG3: work on the recommendations
- H. 12.30 Lunch
- H. 14.00 WG1-WG2-WG3: work on the recommendations
- H. 17.00 Plenary session: restitution of WG contents
- H. 19.30 Dinner

Saturday, 30 May 2026

- H. 09.00 Plenary session: final discussions, voting, perspective, summary/farewell
- H. 13.00 End

H. 20.00 Gala Dinner with authorities and families

Work groups:
WG1 Molecular Diagnosis
WG2 Clinical Diagnosis
WG3 Management

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PROFESSIONIST & PAOs INVOLVED ON INTERNATIONAL CONSENSUS 1st REVISION on BWSp

(alphabetical order)

Begemann Mathias	molecular geneticist	Germany
Bertoletti Monica	PAO	Italy
Blick Jet	molecular geneticist	Holland
Brioude Frédéric	endocrinologist	France
Brzezinski Jack	oncologist	USA
Butti Niccolò	psychologist and psychotherapist	Italy
Carli Diana	clinical geneticist	Italy
Cielo Christopher	sleep medicine	USA
Coze Carole	oncologist	France
Davidson Richard	orthopedic	USA
Dearhoff Matthew	clinical geneticist	USA
De Leon - Crutchlow Diva	endocrinologist	USA
De Pellegrin Maurizio	orthopedic	Italy
Eggermann Thomas	molecular geneticist	Germany
Eggermann Katja	molecular geneticist	Germany
Elbracht Miriam	clinical geneticist	Germany
Eskew Christopher	PAO	USA
Ferrero Giovanni B.	clinical geneticist	Italy
Ganguly Arupa	molecular geneticist	USA
Glatts Carlyn	psychologist	USA
Grønskov Karen	molecular geneticist	Denmark
Hathaway Evan	genetic counselor	USA
Kalish Jennifer M.	clinical geneticist	USA
Kratz Christian P.	oncologist	Germany
Lapunzina Pablo	clinical geneticist	Spain
Lauffer Peter	clinical geneticist	Holland
Ligh Cassie	plastic surgeon	USA
Maas Saskia M.	clinical geneticist	Holland
MacFarland Suzanne	oncologist	USA
Mackay Deborah JG	molecular geneticist	UK
Maher Eamonn	clinical geneticist	UK
Marcucci Lorenzo	orthopedic	Italy
Martin Muñoz Pablo	PAO	Spain
McClelland Louise	molecular geneticist	UK
Michaeli Orli	oncologist	Israel
Mubeen Suhaym	orthodontist	UK
Mussa Alessandro	clinical geneticist	Italy
Netchine Irène	endocrinologist	France
Pajno Roberta	endocrinologist	Italy
Quarello Paola	oncologist	Italy
Riccio Andrea	molecular geneticist	Italy
Rossetti Giulia	maxillofacial surgeon	Italy
Russo Silvia	molecular geneticist	Italy
Shipster Caroleen	speech therapist	UK
Somma Makaela	speech therapist	USA
Soupre Veronique	plastic surgeon	France
Tatton-Brown Katrina	clinical geneticist	UK
Tenorio Jair Antonio	molecular geneticist	Spain
Tümer Zeynep	molecular geneticist	Denmark
Wang Yiming	clinical geneticist	Canada
Weksberg Rosanna	clinical geneticist	Canada

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2nd INTERNATIONAL CONGRESS on BWSp PROGRAMM

Open to families and/or professionals who have registered in advance.

SIMULANEOUS TRANSLATION ITALIAN/ENGLISH AND VICE VERSA

Saturday, 30 May 2026

H. 18.00 Registration and Fhaters' aperitif (open to all men)
H. 20.00 Opening of the Congress

H. 20.00 Gala Dinner

PLEASE NOTE: Young adults (ages 18 and older) of any background, with or without BWSp, will be able to choose where to dine on the evening of May 30th:

- at the hotel at the gala dinner, with everyone

- in a pizzeria, offered by Aibws, only among people their age

Anyone who decides to go eat pizza must **notify by Monday 25 May** by sending an email to congressi@aibws.org

The idiom is not a problem, young Italian adults speak English.

Sunday, 31 May 2026

Moderator: Guido Cocchi - Maurizio De Pellegrins - Pierpaola Tannorella— Rosario Montiroso - Sivlia Russo

H. 09.00 Introduction and welcome- PAO

Part 1: The ABC of BWSp - basic level

H. 09.10 What does BWSp mean? - Elena Bermudez De Castro

H. 09.25 Causes of BWSp - Diana Carli and Arupa Ganguly

Part 2: Management of BWSp

H. 09.40 Who is a Genetic Counselor and what do they do? - Evan Hathaway

H. 09.50 Oncology aspects - Orli Michaeli

H. 10.05 Macroglossia aspects - Makaela Somma and Giulia Rossetti

H. 10.20 Orthopedics aspects - Maurizio De Pellegrin and Richard Davidson

H. 10.35 **Coffee Break**

Part 3: Reflections, new perspectives and preview of the International Consensus revision—intermediate & advanced level

H. 11.05 Tracing Growth Across Time in Beckwith-Wiedemann Spectrum - Saskia Maas and Federica Alberti

H. 11.20 Is prenatal diagnosis possible? - Thomas Eggermann and Zeynep Tümer

H. 11.35 Hyperinsulinism - Diva De Leon Crutchlow and Roberta Pajno

H. 11.50 BWS Conga Line Dance Superpower: interview with Nii Borketey Anna, author of the book, by Marco Bilancioni

H. 12.05 **Questions**

H. 13.00 **Lunch**

H. 14.30 Our Doctors' Performance

H. 15.00 Myofunctional therapy - Irene Valeriani

H. 15.15 Beyond Medical Management: Early Stress and Psychosocial Adjustment in Children with BWSp - Niccolò Butti and Carlyn Glatts

H. 15.30 Twins and BWSp - Giuseppe Reynolds

H. 15.40 Methylation analyses - Jet Bliet

H. 15.55 Maternal-effect variants and BWSp – Silvia Russo and Andrea Riccio

H. 16.10 Wilms tumour predisposition in BWS: a circulating tumour DNA test - Jack Brzezinski

H. 16.25 Preview of the results of the 1st International Consensus revision - Jennifer Kalish and Alessandro Mussa

H. 16.45 **Questions**

H. 18.00 Mothers' aperitif (open to all women)

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2nd INTERNATIONAL CONGRESS on BWSp PROGRAMM

Monday, 1 June 2026

H. 09.00 Aibws Odv Members' Assembly (mandatory for members, recommended for everyone)

H. 10.00 Brainstorming & team-building activities

H. 12.30 Lunch

H. 14.30 Free time together

H. 17.00 2nd Aibws Beach Volleyball Tournament organized by our Papooni

H. 19.00 Aperitif offered by Gaia's family to celebrate the 7° anniversary of the end of chemotherapy

Tuesday, 2 June 2026

Farewells and warm goodbyes, hoping to meet again soon!!!

Please note:

The speakers have already confirmed their attendance, but the program may be subject to minor changes. We recommend checking the Congress website in the days leading up to the event:

www.aibws.org/congresso2026

May 31st will be entirely online, live, for everyone **upon registration** through the Congress website:

www.aibws.org/congresso2026

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CONGRESS SPEAKERS

Alberti Federica	Italy
Anna Borketey Nii	Japan
Bermudez De Castro Elena	Spain
Bliek Jet	Holland
Brzezinski Jack	Canada
Butti Niccolò	Italy
Carli Diana	Italy
Cielo Christopher	USA
Davidson Richard	USA
De Leon - Crutchlow Diva	USA
De Pellegrin Maurizio	Italy
Eggermann Thomas	Germany
Glatts Carlyn	USA
Hathaway Evan	USA
Kalish Jennifer	USA
Maas Saskia	Holland
Michaeli Orli	Israel
Mussa Alessandro	Italy
Pajno Roberta	Italy
Reynolds Giuseppe	Italy
Riccio Andrea	Italy
Rossetti Giulia	Italy
Russo Silvia	Italy
Somma Makaela	USA
Tümer Zeynep	Denmark
Valeriani Irene	Italy
Weksberg Rosanna	Canada

PAOs:

Bertoletti Monica	Italy
Cioara Paula	Romania
Eskew Christopher	USA
Martin Muñoz Pablo	Spain
Valle Daniela	Italy

MODERATORS & others:

Bilancioni Marco
Cocchi Guido
D'Amelio Valentina
De Pellegrin Maurizio
Montirosso Rosario
Russo Silvia
Tannorella Pierpaola
Veronelli Andrea



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VENUE

The entire Congress will take place at Club Hotel Dante di Cervia

The Club Hotel Dante Cervia **** offers concierge services, room service, and shopping services, as well as a seasonal outdoor pool, a sun terrace, and a library. The hotel was built in an Italian style and features 244 classic rooms. Luggage storage, an elevator, and a vending machine are available on site.

Position

Cervia's main attractions, such as the Federico Fellini Museum and Mirabilandia, are nearby. The property is a 10-minute walk from the city center.

The Cervia Milazzo bus stop is 350 meters from Club Hotel Dante Cervia.

Rooms

Each room features individual climate control, a flat-screen TV, a stereo system, and a private bathroom with terry bathrobes.

Food & Drink

A continental breakfast is available every morning. Guests can enjoy a variety of regional dishes at the outdoor restaurant. The hotel invites guests to the garden bar to relax with a drink. Three Star Bath 80 at 950 meters.

Relax

The accommodation offers direct access to a private pool with a poolside bar, a hot tub and a sauna.

Internet

Wi-Fi is only available in public areas and is free.
Cable internet is available in hotel rooms and is free.

Parking

Private parking is possible on site for a fee (€ 6.00 indoors or 3€ uncovered)

Map:

https://www.clubhoteldante.it/dove_siamo

Address

Viale Milazzo 81 ang. Lungomare Deledda
48015, Cervia (RA)

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SERVICES AVAILABLE DURING CONGRESS

Children's Animation: For all children aged 3 and up, from 8:30 am to 6:00 pm on May 31st and from 8:30 am to 12:30 pm on June 1^o, animators will also be able to speak English. **If there are children who do not speak these two languages, we ask you to notify us to look for suitable animators.**

Except for special requirements, both parents are requested to attend the proceedings and **not** to take the children to the Conference room, this to allow the event to be held in a regular and optimal manner.

Interpreters: The official languages of the conference will be Italian and English. There is a simultaneous translation service with headphones for all people who want it.

Hostesses: Upon registration in Congress and during the same, multilingual Hostesses will be present for any information or needs.

Access to Congress: Free if in person, € 20 if online.

Photographer: Mr. Stefano Morelli, a professional photographer, is expected to be present throughout the event, both for institutional photography and for individual families and/or groups. Photos can be purchased directly from Mr. Morelli on site and will be provided with the Congress logo.

Video: Full shot scheduled for May 31st.

Additionally, Kemal Comert, the filmmaker who has worked with us on previous projects, will be present; he was requested to be present for the video footage of the most emotional part of the BWS family's first big meeting.

Children's Snack: Aibws will offer snacks to children on May 31st and June 1st^o.

PLEASE NOTE:

- for weaning children, for celiacs, intolerants, vegetarians or other special needs, cooks are available as long as they are reported early during online pre-registration

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COSTS AND REGISTRATION METHODS

PRELIMINARY INFORMATION:

The program, costs, and services can be viewed and downloaded at www.aibws.org/congresso2026 in both Italian and English.

Access to the Congress is free if in person, a donation of 20€ is required for online access, to contribute to the costs of the live broadcast.

The stay is in full board, so that 3 meals per overnight stay are included (breakfast, lunch, dinner with water and wine).

The registration form can only be completed once. For errors and/or variations, please contact directly: congressi@aibws.org

You will be asked for (mandatory data):

- Last name, first name and date of birth of all participants
- Arrival date and time
- Date and time of departure
- Type of room/s
- For those who do not stay overnight the sessions in which they will be present
- Extra meals (people who are not staying in hotels but stop to eat or if you intend to add a meal beyond those included in the living room)
- Consent for the management of personal data carried out by means of this on-line form

You will also be asked (optional data):

- Special dietary needs (weaning, intolerances, allergies, etc.)
- Nationality
- The presence of one or more people with BWSp

HOW TO PAY

AIBWS ODV will take care of booking the services you request. Within a week of completing the form, you will receive emails from congressi@aibws.org confirming your request and the costs to be incurred.

Please wait for the email before paying for your stay.

Payments must be made directly to the Club Hotel Dante.

The advance of 50% must be paid by March 15, otherwise the reservation will not be considered valid.

The balance is requested no later than May 15th.

Bank transfer to:

ROMAGNA BANCA

IBAN IT92 M0885 2236 0100 8010 2846 36

current account in the name of: DANTEGEST S.R.L.

BIC CODE CCRTIT2TRMB

inserting the reason: "**Participation in ALL IN ONE - Family....**"

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COSTS AND REGISTRATION METHODS

The treatment is provided in FULL PENSION, therefore, including the 3 main meals for each night of stay, with water and wine (beer and other drinks will be paid)

COSTS:

Single room: € 112,00 per night
Double room: € 160,00 per night
Junior suite supplement: € 100,00 per night

Children:
0-7 years not completed € 0,00 per night
7-13 years not completed € 40,00 per night
13-18 years not completed € 64,00 per night

From 18 years and old, the cost is € 80,00 per night

EXTRA MEALS (for those who are not staying at the hotel or plan to add meals to the above):

- up to 8 years old not completed € 16.00 per meal
- 8 years and older € 32.00 per meal

PARKING: by reservation at € 6.00 per night in the garage, or at € 3.00 per night the uncovered parking space

Mandatory extra costs:

- **city tax** (approximately € 3/3.5 per person aged 14 and over), from which disabled people and their companions are exempt if they have the required documentation.
- **Extra Meals** for those who do not stay overnight at € 16.00 per meal until the age of 7, over € 32.00 per meal. There is no payment for these meals but online pre-registration remains mandatory

These costs are to be borne directly on site with the Club Hotel Dante

For any other need or information, send an email to
congressi@aibws.org

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