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EWPKS26



5th EUROPEAN WORKSHOP
ON PALLISTER-KILLIAN SYNDROME



11–13
September 2026



UNAHOTELS Bologna San Lazzaro
San Lazzaro di Savena (BO), Italy

FULL PROGRAMME

5th European Workshop on Pallister-Killian Syndrome
11-13 September 2026 | UNAHOTELS Bologna San Lazzaro
San Lazzaro di Savena (BO), Italy

FRIDAY 11 SEPTEMBER 2026 - ARRIVAL AND WELCOME

20:30-22:30 **Welcome apericena**
Welcome evening for families, clinicians and Workshop guests. An informal opportunity to meet and reconnect.
Restaurant Terrace

SATURDAY 12 SEPTEMBER 2026 - SCIENTIFIC DAY

CHILDREN'S WELCOME AND REGISTRATION

08:00-09:00 **Workshop registration and children's welcome**
Congress Centre Foyer

WORKSHOP OPENING - Room 1 (plenary hall)

09:00-09:20 **Welcome and opening remarks**
Samantha Carletti - President, PKS Italia
Greetings from representatives of the Scientific Committee, institutions and partners

09:20-09:40 **THE VOICE OF PEOPLE WITH PKS - “Living with Pallister-Killian Syndrome: giving the floor to the person”**
Benedetto, young man with Pallister-Killian Syndrome

SESSION I - From diagnosis to lifelong care

Chair: Prof. Guido Cocchi - Alma Mater Professor, University of Bologna; President of the Scientific Committee of PKS Italia APS

09:40-10:00 **From diagnosis to care: the newborn with PKS**
Dr Chiara Locatelli
Neonatology and NICU, IRCCS Azienda Ospedaliero-Universitaria di Bologna - Policlinico di Sant'Orsola

10:00-10:20 **Continuity of care and clinical complexity in childhood**
Dr Giacomo Sperti
Neonatology, IRCCS Azienda Ospedaliero-Universitaria di Bologna - Policlinico di Sant'Orsola

10:20-10:40 **Beyond paediatric age: health needs, transition and care of adults with PKS**
Prof. Giuseppe Zampino
Università Cattolica del Sacro Cuore | Fondazione Policlinico Universitario Agostino Gemelli IRCCS, Rome

10:40-11:00 Coffee break - Foyer

KEYNOTE LECTURE

Introduction to the Keynote Lecture: Prof. Guido Cocchi - Alma Mater Professor, University of Bologna; President of the Scientific Committee of PKS Italia APS

11:00-11:50 **Pallister-Killian Syndrome: what we know and what we still need to discover**
Prof. Ian D. Krantz

*Chief, Division of Medical Genetics; System Vice President Pediatric Genetics
Professor of Pediatrics, Zucker School of Medicine - Hofstra University; Cohen Children's
Medical Center / Northwell Health*

11:50-12:00 Discussion

SESSION II - Genetic research and new diagnostic perspectives

12:00-12:30 **New sequencing technologies for genomic analysis and research on
chromosomal abnormalities**

Dr Tommaso Pippucci

*Computational Genomics, IRCCS Azienda Ospedaliero-Universitaria di Bologna - Policlinico
di Sant'Orsola – Bologna*

SESSION III - Neurological aspects, epilepsy and follow-up

*Chair: Prof. Duccio Maria Cordelli - Child Neuropsychiatry, IRCCS Institute of Neurological Sciences of
Bologna; University of Bologna*

12:30-13:10 **Neurological phenotype, epilepsy and long-term follow-up in Pallister-Killian
Syndrome**

Dr Luca Soliani

Dr Emilia Ricci

*UOC Child Neuropsychiatry, IRCCS Institute of Neurological Sciences of Bologna
SC Developmental Neurology - Regional Epilepsy Centre, ASST Santi Paolo e Carlo, Milan*

13:10-14:10 Workshop lunch - Room 3

INTERNATIONAL ROUND TABLE

14:10-15:10 **Building the future of PKS research**

Chair: Prof. Ian D. Krantz

Coordination: Samantha Carletti - PKS Italia

*Cohen Children's Medical Center / Northwell Health; Zucker School of Medicine - Hofstra University,
USA*

*Towards the first International PKS Research Symposium and the International PKS Research
Consortium, with representatives from PKS Kids USA, PKS UK and PKS Foundation of Australia.
Objective: to initiate a shared path towards the establishment of the International PKS Research
Consortium and the organisation of the first International PKS Research Symposium.*

SESSION IV - Participation, inclusion and family life

Chair: Prof. Duccio Maria Cordelli - Child Neuropsychiatry, IRCCS Institute of Neurological Sciences of Bologna; University of Bologna

15:10-15:40 **School within Circles of Support - A student-centred education for pupils with special educational needs**
Katarzyna "Kasia" Świeczkowska
Co-founder and Director of PSONI Gdańsk educational services; Vice-President of the Polish Association for Persons with Intellectual Disabilities (PSONI), Gdańsk

15:40-16:00 **Inclusive schooling: Manuel's journey**
Rita Torelli - Manuel's mother
Gabriella Garoia - Headteacher, "Andrea Canevaro" Comprehensive Institute, Bertinoro
Carla Pezzi - Primary School Teacher / Monia Empoli - Lower Secondary School Teacher

16:00-16:20 **Coffee break**

FAMILY WELLBEING AND PSYCHOLOGICAL SUPPORT

16:20-16:50 **Caring for those who care**
Dr Francesca Latella
Psychologist and psychotherapist, caregiver expert
Psychological and psychodynamic aspects of the family system of the person with PKS: caregivers and siblings in focus

16:50-17:20 **Gaia's Embrace. Psychological support for the family: listening, relationships and ongoing support**
Introduction by Prof. Emilio Franzoni - Child Neuropsychiatrist
Elisabetta Ferrè - Gaia's mother
Dr Simona Simone - Psychologist, FANEP - Neuropsychology and Integrated Medicine

SESSION V - Multidisciplinary care and quality of life

Chair: Prof. Guido Cocchi - Alma Mater Professor, University of Bologna; President of the Scientific Committee of PKS Italia APS

17:20-17:50 **Gastroenterological and nutritional aspects and feeding management in PKS**
Dr Flavio Labriola
Departmental Programme of Paediatric Gastroenterology, Ospedale Maggiore, Bologna

17:50-18:15 **Oral health in Pallister-Killian Syndrome: prevention, treatment and access to care**
Dr Marco Montevercchi / Dr Giovanni D'Alessandro
University of Bologna, Dental Clinic

18:15-19:00 **Orthopaedic involvement in Pallister-Killian Syndrome: hip and spine issues**
Prof. Cesare Faldini
Director, Orthopaedics and Traumatology Clinic I, Rizzoli Orthopaedic Institute, Bologna

19:00-19:05 **Closing remarks**
Samantha Carletti and the EWPKS26 Scientific Committee

SATURDAY 12 SEPTEMBER 2026 - GALA DINNER

20:30-24:00	Gala Dinner - 15 years of PKS Italia APS - Room 1 (plenary hall) <i>Celebratory evening marking the 15th anniversary of PKS Italia. Dinner, music and special moments for families, friends and collaborators of the Association.</i>
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SUNDAY 13 SEPTEMBER 2026 - FAMILY DAY

08:30-13:00	Individual medical consultations Available in parallel with the morning activities, by appointment only.
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10:00-13:00	Activities, workshops and sharing groups - Room 2 <i>Group activities for families, siblings and young people with PKS. A space for exchange and sharing among caregivers.</i>
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10:30-12:30	Psychological support group - ORANGE GROUP - Room 4
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13:00-14:30	Closing lunch - Room 3 <i>Lunch for all participants.</i>
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14:30-17:00	Individual medical consultations, by appointment only.
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14:30-16:30	Psychological support group - BLUE GROUP - Room 4
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17:00	See you at the next edition! Farewell and departures.
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