

2nd International Workshop on Klinefelter Syndrome

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Münster, Germany

Venue

Factory Hotel

An der Germania Brauerei 5
48159 Münster, Germany

Program Organizing Committee

Alberto Ferlin
Italy

Hanna Swaab
Netherlands

Alan Rogol
USA

Anders Juul
Denmark

Jörg Gromoll
Germany

Local Organizing Committee

Sabine Kliesch

Jörg Gromoll

Frank Tüttelmann

Joachim Wistuba

Michael Zitzmann

Speakers

Art Arnold
USA

Anders Bojesen
Denmark

Christine Disteche
USA

Alberto Ferlin
Italy

Claus Gravholt
Denmark

Joost Gribnau
Netherlands

Olaf Hiort
Germany

Anders Juul
Denmark

Sabine Kliesch
Germany

Birgit Köhler
Germany

Hervé Lejeune
France

Gabriel Marais
France

Eberhard Nieschlag
Germany

Armin Raznahan
USA

Alan Rogol
USA

Carole Samango-Sprouse
USA

Manuela Simoni
Italy

Anne Skakkebæk
Denmark

Niels Skakkebæk
Denmark

Liborio Stuppia
Italy

Hanna Swaab
Netherlands

Nicole Tartaglia
USA

Frank Tüttelmann
Germany

Joana Viana
UK

Joachim Wistuba
Germany

Michael Zitzmann
Germany

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A KING for Klinefelter Syndrome: The SIAMS task force

Members of the KING group (in alphabetic order): ¹G. Balercia, ² M.Bonomi, ³ A.E. Calogero, ⁴ G. Corona, ⁵ V.A. Giagulli, ⁶ A. Ferlin, ⁶ C. Foresta, ⁷ S. Francavilla, ⁶ A. Garolla, ⁸ E. Jannini, ⁹ F. Lanfranco, ¹⁰ M. Maggi, ¹¹D. Pasquali (coordinator), ¹² R. Pivonello, ¹³ A. Pizzocaro, ¹⁴ A. Radicioni, ¹⁵ V. Rochira, ¹⁰ L. Vignozzi

¹University of Marche, Ancona, ²University of Milan and IRCCS Istituto Auxologico Italiano, Milan, ³University of Catania, ⁴Endocrinology Bologna, ⁵Endocrinology Bari, ⁶University of Padova, ⁷University of L'Aquila, ⁸University Tor Vergata, Rome, ⁹University of Turin, ¹⁰University of Florence, ¹¹Second University of Naples, ¹²University Federico II, Naples, ¹³IRCCS, Istituto Clinico Humanitas, Rozzano-Milan, ¹⁴University La Sapienza, Rome, ¹⁵University of Modena & Reggio Emilia, Italy

Klinefelter Syndrome (KS) is a fascinating condition for clinicians and researchers due to the variety of open questions still waiting for an answer. KS is one of the most frequent chromosomal disorders, occurring in 1:500 to 1:1000 live male births. Although significant research has been conducted, KS remains frustratingly underdiagnosed with a remarkable portion of cases being unidentified, among which only 10% are in the prepubertal age while 25-50% in the adulthood. As a consequence, medical research results often become clouded due to the relatively small number of patients reported in scientific papers. To overcome this difficulty, the Italian Society of Andrology and Sexual Medicine (SIAMS) relayed to the expertise of Italian researchers and clinicians in this field to constitute an outstanding working group on KS. Thus, a network named KING (Klinefelter Italian Group), aiming at sharing the know-how and collecting KS patients, to improve the knowledge of this syndrome, was created. KING is composed by fifteen high-specialized Endocrinology and Andrology units, either academic or institutes for treatment and research (IRCCS), located throughout Italy. Each unit has a principal investigator and a KING coordinator has been identified. It has been created a common data register for an initial retrospective and registration study. Each KING unit has collected retrospective demographical data from KS patients among those regularly attending the units, after written informed consent has been obtained. Results: Up to now, four hundred and two KS from 12 out of 15 units have been registered. Their mean age was 41.6 ± 13.0 years (range: 8–76 years). Only seventeen KS were diagnosed before the age of 18 years. Finally, the estimated total number of KS will be nearly 800 cases. Conclusions: Our preliminary data showed a higher rate than expected of underdiagnosed KS compared to the Italian population that is made up of about 27,000,000 male subjects. This result, even if partial, raises the question of the true prevalence of KS, at least in Italy. In the European Northern countries, national patients' register data have been used for statistical purposes for 50 years, providing the opportunity to collect significant results. Furthermore, many registers can be linked. The register system itself has great impact on how statistical data are generated and can be a powerful tool to clarify the un-answered questions, especially in the study of rare diseases.