

**A systematic elucidation of
Differences of Sex Development**
COST-Action BM1303

www.dsdnet.eu



1st Training School

Holistic care and research in DSD

- an interdisciplinary and collaborative approach with long term perspective -

8 – 10 June 2015

Congress center

“Het Pand”

Ghent, Belgium

Adolescence /Adulthood Adult with DSD Androgen receptor Animal models in DSD Cellular modeling of DSD Delayed puberty Dilation Discussion assignment DSD: non normative holistic care **Genetic and developmental aspects** Gonadal dysgenesis Growing child **Hormonal effects** I-DSD Indications and timing of gonadectomy Informing adolescent and parents and parents newborn **Interdisciplinary team** Language and communication Outcome research PAIS Social integration and DSD SRY and beyond **Steroidogenesis** Study of rare conditions Understanding the genetic causes of DSD Urosurgery Vaginoplasty



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Dear Trainers and Trainees

It is a pleasure to welcome you to the 1st COST DSDnet Training School under the theme “Holistic care and research in DSD: An interdisciplinary and collaborative approach with long term perspective.” The European Cooperation in Science and Technology (COST) is the longest running European framework supporting trans-national cooperation among researchers, scholars, and professionals across Europe and beyond. At this Training School we have 20 Trainers from around the world as well as 30 Trainees from 18 participating COST countries as well as two observers from International Partner Countries. Furthermore, both the Trainers and the Trainees represent very different specialities and professions, ranging from basic research to clinical scientists to psychologist. We would like to foster interaction and networking among you all in all directions.

It is our main goal to provide training in various steps from a holistic view, ranging from genetics and development to gender aspects and communication. This should lead to a truly interdisciplinary view on sex development and its variations as well as aspects of care and management and enhance discussions amongst you all. At the end we not only hope to enlighten you personally to a very special field of human science, but also to provide the basis for further interaction and collaboration among young and experienced scientists.

We wish you a very pleasant and memorable Training School and are truly looking forward to a wonderful adventure on behalf of the whole COST Action.

Olaf Hiort
Action Chair

Sten Drop
Lead POC

Martine Cools
Local Organizer

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Monday, 08.06.2015	Tuesday, 09.06.2015	Wednesday, 10.06.2015	The Faculty
13:00	Registration		
13:45	Building an InterDisciplinary Team		1st Plenary Session
	Welcome and introduction		Olaf Hiort / Sten Drop
	When parents need to grow with their child		Ellie Magritte
	Navigating DSD, puberty, school, & relationships: How affected teens become empowered young adults (and how you can help!)		Miriam Muscarella
	Understanding the genetic causes of DSD		Ken McElreavey
	Coffee/Tea		
	Attending to emotion across the lifespan		Lih-Mei Liao
	The COST Programme and the DSDnet		Olaf Hiort
17:00	Getting to know each other in the InterDisciplinary Team <i>- a special training course coordinated by Dr Benno Bonke, PhD, psychologist/educationalist (ErasmusMC, Rotterdam) aiming at facilitating communication in the context of different cultural, societal, and professional backgrounds -</i>		Field trip
18:30	End of day I		
	Dinner		
	Short walk through Ghent		

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Monday, 08.06.2015	Tuesday, 09.06.2015	Wednesday, 10.06.2015	The Faculty
08:30	Genetics and Development		2nd Plenary Session
	A girl with gonadal dysgenesis		Martine Cools
	Gonadal development and tumor risk in DSD; Indications and timing of gonadectomy		Martine Cools
	Cellular modeling of DSD		Anu Bashamboo
	MAPK signals in mouse and human sex determination		Andy Greenfield
	<i>Coffee/Tea</i>		
	SRY and the beginning of the male determining cascade		Peter Koopman
	Registering in I-DSD		Faisal Ahmed
12:30	<i>Lunch</i>		
13:30	Hormones and their Effects in Sex Development		3rd Plenary Session
	A baby with PAIS		Paul-Martin Holterhus
	Androgen action		Paul-Martin Holterhus
14:15	Introduction to molecular genetic methodology (Assignment)		1st Group Session*
15:10	Introduction to molecular genetic methodology (Assignment)		2nd Group Session*
16:00	End of Day II		
	Visiting Bruges		
	Dinner		

* It is the intention to form multidisciplinary break out session groups representing the various disciplines.

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08:30	Treatment and Care		4th Plenary Session
	We are expecting a girl		Sten Drop
	Update steroidogenesis		Nils Krone
	Vaginoplasty		Marta Berra
	Under pressure: Vaginal dilation anno 2015		Nina Callens
	<i>Coffee/Tea</i>		
	Male urogenital reconstruction		Alexander Springer
	Outcome Research		Vicky Pasterski
12:45	Lunch		
14:00	Living with DSD across the ages		5th Plenary Session
	A girl with delayed puberty		Sten Drop
	Language and communication		Charmian Quigley
14:45	Informing parents newborn (Assignment)		3rd Group Session*
15:45	Informing adolescent and parents (Assignment)		4th Group Session*
16:30	<i>Discussion Assignment</i>		<i>Panel</i>
	<i>Concluding remarks: take home messages</i>		
18:00	End of Training School		
19:00	Drinks and Farewell Dinner		

* It is the intention to form multidisciplinary break out session groups representing the various disciplines. The sessions will be coordinated by Dr Benno Bonke, PhD, psychologist/educationalist (ErasmusMC, Rotterdam) .



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Faisal Ahmed	(UK)	University of Glasgow	
Anu Bashamboo	(FR)	Institute Pasteur, Paris	
Marta Berra	(IT)	University of Bologna	
Nina Callens	(US)	University of Michigan Medical School	
Martine Cools	(BE)	Ghent University	
Sten Drop	(NL)	Erasmus Universitair Medisch Centrum Rotterdam	
Andy Greenfield	(UK)	MRC Harwell, Oxfordshire	
Olaf Hiort	(DE)	Universität zu Lübeck	
Paul-Martin Holterhus	(DE)	Christian-Albrechts-Universität zu Kiel	
Peter Koopman	(AUS)	The University of Queensland	
Nils Krone	(UK)	University of Birmingham	
Lih-Mei Liao	(UK)	University College London	
Ellie Magritte	(UK)	dsdfamilies.org	
Ken McElreavey	(FR)	Institute Pasteur, Paris	
Miriam Muscarella	(US)	dsdfamilies.org	
Vicky Pasterski	(UK)	University of Cambridge	
Charmian Quigley	(AUS)	Sydney Children's Hospital	
Alexander Springer	(AT)	Medical University Vienna	