



TENTATIVE PROGRAM

ENCA MEETING GENOA 2016, Thursday and Friday – 29/9/16 – 30/9/16 – Transition and research

THURSDAY, 29/9/2016: RESEARCH AND INTRODUCTIONS

10.00 – 10.30	Opening, introduction of program, welcome to all, achievements of the committee till now and introduction of everybody on the meeting	Wendy COSTELLO – President of ENCA
10.30 – 11.00	Exciting developments in how to choose the right medicine in JIA, for each child and how to predict response to the treatment i.e.	Lucy R WEDDERBURN, professor and Consultant of Paediatric Rheumatology, UCL Institute of Child Health London
11.00 - 11.30	Discussion and questions to Lucy and research	Lucy R WEDDERBURN + Wendy COSTELLO as leader of discussion
11.30 – 11.45	Coffee break	
11.45 – 12.15	Introduction of ENCA members (associations): IZRAEL, FRANCE, ENGLAND	Yona EGERT (IZ), Anton GRUSS (FR), Glenda DALTON (UK)
12.15 – 12.45	Introduction of JIA treatment protocols and transition experience in Slovenia	PROF. DR. Tadej AVČIN, SLOVENIA, Ljubljana University Medical Centre, Ljubljana; Rheumatology, president of Slovenian Association
12.45 – 13.30	LUNCH	
13.30 – 14.00	Introduction of happening and ending the SHARE project and results	Bas VASTERT PhD, MD and Nico WULFFRAAT PhD, MD Subafdelingshoofd Cluster B Divisie Kinderen, Cluster immunologie, reumatologie, hematologie en infectiologie Wilhelmina Kinderziekenhuis
14.00 – 14.30	“Whose disease is it anyhow?” Three short introductory statements followed by a round table interview with a parent, health professional and pediatric rheumatologist about novel initiatives to collaboratively set a research agenda and participate.	Casper SCHOENMAKER PhD, MA, Janjaap van der NET PhD, PT, Nico WULFFRAAT PhD, MD, interviewer: Bas Vastert PhD, MD
14.30 – 15.00	Introduction of PARE organization	Dieter WIEK, Chairman of the Standing Committee of PARE
15.00 – 15.15	Coffee break	
15.15 – 15.45	Introduction of serious game “AJIKO” - This serious game has been developed so far in French and English by the French associations ANDAR with the help of KOURIR and the support of the ABBVIE laboratory. It will be available this summer and will give answers to medical questions regarding JIA on a ludic media appropriate for children.	Dr Jean-David COHEN, Sonia TROPE (ANDAR)
15.45 – 16.00	PHOTOSHOOTING + OTHER	



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FRIDAY, 30/9/2016: TRANSITION

10.00 – 10.30	Transition and problems in transition in Germany	Prof. Kirsten MINDEN – RESEARCH CENTER, BERLIN Germany
10.30 – 11.00	Introduction of transition through patients eyes in Netherlands	Annelies HOEKSTRA Netherlands
11.00 - 11.30	Transition in Belgium	Dr Carine WOUTERS PhD MD, Pediatric Rheumatology and Immune-Inflammatory Diseases, University Hospital Leuven Belgium
11.30 – 11.45	Coffee break	
11.45 – 12.15	Session: Patient , Doctor (together): transition through doctor`s eyes and through patient`s eyes	Dr. CARINE WOUTERS and 2 PATIENTS (WENDY leading discussion) – patients: Gillian (UK) + Annelies (Netherlands)
12.15 – 12.45	Introduction to ENCA members– 3 countries	3 countries/associations, who will introduce themselves and their work, activities NETHERLANDS (Anita), HUNGARY (DR. ORBAN) AND LATVIA (Mrs. Sarmite)
12.45 – 13.00	Questions	
13.00 – 13.30	LUNCH	
13.30 – 14.00	INTRODUCTION OF Young Pare	Dora Papastavrou – representer of Young Pare
14.00 – 14.10	Questions, debate/ Young Pare + ENCA	Wendy COSTELLO – President of ENCA
14.10 – 14.30	A patient project on 'invisible illness' in schools - introduction	Sophie Ainsworth UK
14.30 – 15.00	Meeting next year + main topics for next year	Wendy COSTELLO – President of ENCA