



4TH ANNUAL INTERNATIONAL ECD PATIENT & FAMILY GATHERING PARIS | 2016

WELCOME DINNER
September 15, 2016
7:00 - 8:30 pm

CAREGIVER & PATIENT SOCIALS
September 16, 2016
6:00 – 7:00 pm

Patient & Family Gathering Meeting Agenda DRAFT

September 16, 2016 | 9:00 am – 5:00 pm

TIME	PRESENTATION TOPIC	PRESENTER
9:00 - 9:10	Welcome	Prof. Julien Haroche, MD, PhD Hôpital Pitié-Salpêtrière Paris, FRANCE
9:10 - 9:30	ECD101 + Mutations & Findings Overview	Juvianee Estrada-Veras, MD National Institutes of Health Bethesda, Maryland, USA
9:30 - 10:10	Study findings, updates & needs (5 min each)	<ol style="list-style-type: none"> 1. Prof. Julien Haroche, MD, PhD Hôpital Pitié-Salpêtrière Paris, FRANCE 2. Achille Aouba, MD, PhD Hôpital Necker-Enfants Malades Paris, FRANCE 3. Prof. Lorenzo Dagna, MD IRCCS H San Raffaele Scientific Institute and Vita-Salute San Raffaele University Milan, ITALY 4. Augusto Vaglio, MD, PhD Parma University Hospital Parma, ITALY 5. Filip Janku, MD, PhD The University Of Texas MD Anderson Cancer Center Houston, TX, USA 6. Eli L. Diamond, MD Memorial Sloan Kettering Cancer Center New York, NY, USA 7. Juvianee Estrada-Veras, MD National Institutes of Health Bethesda, Maryland, USA
10:10 – 11:10	Doctor Q&A	Same as above

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TIME	PRESENTATION TOPIC	PRESENTER
11:10 - 11:40	Break	
11:40 – 11:55	ECD Care Management	Prof. Lorenzo Dagna, MD IRCCS H San Raffaele Scientific Institute and Vita-Salute San Raffaele University Milan, ITALY
11:55 – 12:10	ECD – Neurological Issues	Eli L. Diamond, MD Memorial Sloan Kettering Cancer Center New York, NY, USA
12:10 – 12:25	ECD – Kidney Issues	Augusto Vaglio, MD, PhD Parma University Hospital Parma, ITALY
12:25 – 12:40	GROUP PHOTO	
12:40 – 1:55	LUNCH	
1:55 – 2:25	ECD Scan & Radiology Panel (Q & A)	Philippe Cluzel, MD Hôpital Pitié-Salpêtrière Paris, FRANCE 2. Philippe Grenier, MD Hôpital Pitié-Salpêtrière Paris, FRANCE 3. Philippe Maksud, MD Hôpital Pitié-Salpêtrière Paris, FRANCE
2:25 – 2:40	ECD – Lung and Heart Issues	Giulio Cavalli, MD IRCCS H San Raffaele Scientific Institute and Vita-Salute San Raffaele University Milan, ITALY
2:40 – 2:55	ECD – Pain Issues	Prof. Lorenzo Dagna, MD IRCCS H San Raffaele Scientific Institute and Vita-Salute San Raffaele University Milan, ITALY
2:55 – 3:10	ECD – Hormone Issues	Carine Courtillot, MD Hôpital Pitié-Salpêtrière Paris, FRANCE
3:10 – 3:40	BREAK	
3:40 – 3:55	ECD – Skin Issues	Stephane Barete, MD Hôpital Pitié-Salpêtrière Paris, FRANCE
3:55 – 4:25	Doctor Q&A	All remaining speakers
4:25 – 5:00	ECDGA Close & Evaluations	ECDGA