



WAPO Summit 2019 Program
May 17 – 18 – 19, 2019

Friday, May 17:

Meeting moderator: Kathy Redmond

- 14:00 Welcome & Introduction - *Andrei Andrusov - Chairman*
- 14.10 Introduction by patient advocates and WAPO guests
- 14:30 Best practices by patient advocates (→ 4-5 presentations)
- 15:45 Coffee break
- 16:15 “How to effectively communicate with patients in difficult situations”
 1. *Dr. Qingfang Sun (Ruijin Hospital, Shanghai) - 30 minutes*
 2. *Mrs. Karen Powel (Cancer Support France, Languedoc) - 60 minutes active session*
- 17:45 End of general program
- 18:00 **WAPO Board meets with pharma representatives**
- 19:00 Welcome dinner

Saturday, May 18:

Meeting moderator: Kathy Redmond

- 08:30 Strategic planning for patient organizations
Kathy Redmond (Redmond Consulting)
- 10:00 Coffee Break
- 10:15 Presentation and Workshop
“A journey through clinical research, working together to improve the experience” - *Rachel Jones (Swi..ch, UK)*

11:30 *End morning session*

11:40 **Departure from WAPO to ECE2019 venue by bus**

12:00 Lunch (WAPO participants arrive by bus to ECE2019 venue)

Meeting moderator: Kathy Redmond

- 12:50 Welcome and meeting objectives
Sofia Llahana, ESE Nurses Chair
Andrei Andrusov, WAPO President
Alexandrine Bost, French Nurses Group Chair



13:00 Session 1: Presentations followed by a Q&A session

Chairs: Andrei Andrusov, Elena Shelestova and Alexandrine Bost

13.00 Residual Morbidity and impact on Quality of life in pituitary disease
Elena Valassi, Consultant Endocrinologist (Barcelona, Spain)

13:25 Shared decisions and making the best of your patient consultations
Cecilia Follin, Endocrine Nurse Practitioner (Lund, Sweden)

13:50 From question to evidence: developing a research or audit question and conducting projects to evaluate your practice or organization
Anne Marland, Nurse Practitioner & PhD Researcher (Oxford, UK)

14:15 Coffee/tea break and networking

14:45 Session 2: Developing a consensus for patient education and standards care services for patients with Adrenal Insufficiency

Chairs: Sherwin Criseno and Muriel Marks

14:45 Therapeutic Education of Patients with Adrenal and Pituitary Disorders: the French initiative
Alexandrine Bost and Brac De La Perrier (Lyon, France)

15.05 Adrenal insufficiency in patients with pituitary and adrenal conditions and evidence of impact of patient education
Christine Yedinak, Professor of Endocrinology Nursing (Oregon, USA)

15.20 Patient perspective: primary adrenal insufficiency
Johan Beun, AdrenalNet (the Netherlands)

15.30 Patient perspective: secondary adrenal insufficiency in pituitary conditions
Sandra Mesri (WAPO, Argentina)

15.40 Developing a consensus for patient education and standards for care services for patients with adrenal insufficiency: an international collaboration
Sofia Llahana, Consultant Nurse in Endocrinology, ESE Nurses (London, UK)

16.00 Open discussion and Q&A on Consensus proposal and next steps

16.30 Conclusions, take home messages and Group picture

16:45 *End combined session & Departure WAPO by bus*



17:30 WAPO Members Pictures & Wrap-up
18:00 – 18:45 De-brief meeting between industry sponsors and WAPO Board of Directors
19:30 Dinner

Sunday, May 19:

09:30 Poster contest
09:45 **Annual General Meeting** - only for full WAPO member organizations
12:30 Farewell & Lunch

14:00 – 17:30 NEW Board of Directors