



Programme for Nordic Rett Syndrome Conference 19 - 20 April 2018

THURSDAY 19 APRIL

- 9.30 REGISTRATION AND COFFEE
- 10.15 WELCOME AND OPENING **Katarina Öryd, RSIS**
- Topic: **HEALTH**
- 10.45 KEYNOTE PRESENTATION: Breathing disturbances in Rett syndrome
Malin Rohdin
- 11.30 Epilepsy in Rett syndrome – from a lifetime perspective **Mari Wold Henriksen**
- 12.00
- LUNCH AND EXHIBITIONS
- Topic: **MOTOR FUNCTION**
- 13.15 KEYNOTE PRESENTATION: Motor function and activity in Rett syndrome
Jenny Downs (via video link)
- 14.00 Rett syndrome - a problematic diagnosis? **Ola Skjeldal**
- 14.30 COFFEE AND EXHIBITIONS
- PARALLEL SESSIONS
- | | Room: Cosmos | Room: Jupiter |
|-----------------|---|--|
| 15.00 | Orofacial disturbances
Lotta Sjögren | Health-enhancing participation in
Rett syndrome
Michelle Stahlhut |
| 15.50-
16.35 | Can girls with Rett syndrome (re)learn
gross motor skills after regression?
Ann-Marie Bisgaard | Gymnastics for all
Birgitta Green &
Jessica Green |
- 17.00 RSIS ANNUAL MEETING
- 19.00 CONFERENCE DINNER



FRIDAY 20 APRIL

9.00

INTRODUCTION

Topic: **COMMUNICATION/ EDUCATION**

9.15

KEYNOTE PRESENTATION: Strategies that enable learning

Lisbeth Nilsson

10.00

COFFEE AND EXHIBITIONS

10.30

Communication guidelines **Helena Wandin**

Topic: **QUALITY OF LIFE**

11.00

KEYNOTE PRESENTATION: Sleep and Rett syndrome

Poul Jennum

11.45

Rett syndrome from childhood to old age **Ann-Marie Bisgaard**

12.15

LUNCH AND EXHIBITIONS

PARALLEL SESSIONS

Room: Cosmos

Room: Jupiter

13.30

Emergent literacy for girls with Rett syndrome - overcoming limiting beliefs

Stefanie K. Sachse

Delaktig i ögonblicket – material för ögonstyrd dator

Eva Holmqvist

14.20

What do parents of girls and women with Rett syndrome worry about?

Jane Lunding Larsen

Eye gaze technology – the habilitation process

14.45

Activity

Åsa-Sara Sernheim

Lotta Lintula

15.10

SUMMARY AND CLOSING **Maria Dellskog, RSIS**

15.30

COFFEE