

Seminar and Webinar on “Hereditary Thoracic Aortic Aneurysm and Dissection” (HTAAD).

28th-30th of November 2016.

Welcome to this seminar with lectures and discussions on
Hereditary Aortic Aneurysm and Dissection disorders.

Location: Monday 28.11 & Tuesday 29.11: Oslo University Hospital,
Rikshospitalet, seminar room, B2.U001
Wednesday 30.11: TRS Resource Centre,
Sunnaas Rehabilitation Hospital, Nesodden

Clinicians and researchers from Norway, Germany, Belgium and USA
will participate and give lectures.

*Specially invited guest is Reed Pyeritz, researcher and geneticist from
Perelman School of Medicine, University of Pennsylvania in Philadelphia,
a leading scientist on Marfan syndrome and related disorders.*

The Seminar is arranged by TRS Resource Centre for Rare Disorders Sunnaas
Rehabilitation Hospital, Norway
in cooperation with ; Oslo University Hospital, Norway, Marfan Clinics at the
University Hospitals in: Hamburg - Germany and Ghent - Belgium
and The Marfan syndrome associations in Norway, Belgium and Germany;

For Registration to participate – se next page

Seminar fee: There will be none.

Lunch and coffee/ tea breaks for registered seminar participants (whole day Monday/ Tuesday/ Wednesday) will be included and covered by TRS

REGISTRATION:

You may register for either Seminar attendance or follow the webinar from your own computer. There is a limited number of places in the seminar auditorium, first to register gets priority.

Deadline for registration for the seminar is 15.november 2016.

To register for the seminar, copy the text below, fill out your details and e-mail it to: trs@sunnaas.no

Name:....., Occupation....., Work place.....,
e-mail.....

Mark which days you want to participate:

- Monday 28.nov. Hereditary Thoracic Aortic Aneurysm and Dissection.
- Tuesday 29.nov. Marfan syndrome. Diagnostic and treatment challenges
- Wednesday 30.nov. Work seminar. How can we work together to the benefit of our patients?

Lunch: Do you have any allergies, vegetarian food etc? Yes
Specify.....

To register for the webinar, copy the text below, fill out your details and e-mail it to: synnove.solberg@sunnaas.no

Mark which days you want to participate:

- Monday 28.nov. Hereditary Thoracic Aortic Aneurysm and Dissection.
- Tuesday 29.nov. Marfan syndrome. Diagnostic and treatment challenges

Webinar attendants will receive an e-mail with link to the webinar. The webinar will also be available at TRS web page

Monday 28.November 2016,

Seminar/ webinar

Topic: Hereditary Thoracic Aortic Aneurysm and Dissection (HTAAD)
Diagnostics and treatment.

Location Oslo University Hospital, Rikshospitalet, B: Seminarrom 1 B2.U001

08.30-09.00 Registration and coffee /tea

Chair 09.00 – 12.00: Prof. Arnt Fiane, *Department of thoracic and cardiovascular surgery.*

09.00-09.15 Welcome ☺
*Arnt Fiane, Professor
Department of thoracic and cardiovascular surgery, Oslo University Hospital, Norway*

09.15 -09.30 Why the subject HTAAD?
*Nina Riise, MD.
TRS Resource Centre for Rare disorders*

09.30-10.35 HTAAD, Nomenclature, causes and clinical spectrum.
*Reed Pyeritz, 'William Smilow Professor of Medicine'
Perelman School of Medicine, University of Pennsylvania*

10.35- 10.45 Discussion

10.45-11.00 Break: Fruit, coffee / tea

11.00-11.30 Next generation sequencing in diagnosis of HTAAD at Oslo University Hospital,
*Geneticist from
Department of clinical genetics, Oslo University hospital, Norway*

11.30-11.40 Discussion

11.40-12.05 Clinical spectrum of persons with HTAAD registered at TRS
*Nina Riise, MD.
TRS Resource Centre for Rare Disorders*

12.05-12.15 Discussion

12.15-13.15 Lunch

Chair 13.15 – 15.15: Odd Geiran, Prof. Emeritus, *Department of thoracic and cardiovascular surgery, Oslo University Hospital, Norway*

13.15-14.05 Clinical follow up and pharmacological treatment of HTAAD
*Reed Pyeritz, Reed Pyeritz, 'William Smilow Professor of Medicine'
Perelman School of Medicine, University of Pennsylvania*

14.05-14.15 Discussion



Monday 28.nov. continued

- 14.15-14.50 **Surgical experience with HTAAD**
Kirsten Krohg-Sørensen, Ass. Professor, Consultant Vascular Surgery.
Department of thoracic and cardiovascular surgery, Oslo University hospital, Norway
- 14.50-15.00 **Discussion**
- 15.00-15.30 **Summing up and discussion.**
Nina Riise, MD.
TRS Resource Centre for Rare Disorders
- 18.00? **Joint dinner for those who want to – on own cost**

Tuesday 29.November 2016

Seminar/ webinar

Topic: Marfan syndrome, diagnostic and treatment challenges

Location Oslo University Hospital, Rikshospitalet, B: Seminarrom 1 B2.U001

08.30-09.00 Registration and coffee /tea

Chair 09.00 – 12.00: Not determined

09.00-09.10 Welcome ☺ Not determined

09.10-10.45 **Children with Marfan syndrome. Diagnostics and treatment**

09.10-09.25 Why is this important? Introduction

Nina Riise, MD.

TRS Resource Centre for Rare disorders

09.25-10.05 How to diagnose and follow up?

When to start medical treatment? – current evidence

MD Laura Muiño Mosquera

Department of Cardiology and Center for Medical Genetics, Ghent University Hospital

10.05-10.25 Discussion

10.25-10.40 Break: Fruit, coffee / tea

10.40-11.00 **Sleep apnea from a clinical perspective**

Hanne Berdal Sørensen, Head Senior Consultant

Department of Ear, Nose & Throat, Head and neck surgery. Lovisenberg Diakonale Hospital

11.00-11.40 **Marfan syndrome and sleep apnea**

Prevalence. Implications for aortic complications, fatigue and quality of life

Nele Gessler, MD.

University Heart Center Hamburg

11.40-12.00 Discussion

Tuesd. 29. Nov. continued

12.00-13.00 Lunch

Chair 13.00 – 16.00: Ass. Professor Kirsten Krohg-Sørensen,
Dep. of thoracic and cardiovascular surgery, Oslo University Hospital

13.00-14.00 Restricting physical activity or making it possible? What can we safely recommend?

13.00-13.15 Change of attitude from restriction to encouragement
Reed Pyeritz, 'William Smilow Professor of Medicine'
Perelman School of Medicine, University of Pennsylvania

13.15-13.30 What is the current documentation for physical restrictions in Marfan syndrome?
Jostein Grimsø, MD, PhD
LHL-clinics Feiring (Feiring Heart Clinic), Norway

13.30-13.45 What advice can we give? Cardiology perspective
Julie De Backer, Prof. Dr. MD
Department of Cardiology and Center for Medical Genetics, Ghent University Hospital

13.45-14.00 Discussion

14.00-14.15 Break with coffee/ tea

14.15-14.35 Experiences with rehabilitation of Marfan syndrome patients in Germany,
Meike Rybczynski, PhD MD
University Heart Center Hamburg

14.35-15.00 Selecting participants for rehabilitation of Marfan syndrome patients in Germany.
Cardio-vascular overview over the participants so far
Meike Rybczynski, PhD MD.
University Heart Center Hamburg

15.00-15.45 I-SWOT (Analysis of Strengths, Weaknesses, Opportunities, and Threats as a Tool for Translating Evidence into Individualized Medical Strategies),
Yskert von Kodolitsch, Prof. Dr. MD., MBA
University Heart Center Hamburg

15.45-16.00 Summing up, End of the day. *Not determined*

19.00 Informal dinner for invited guests, at TRS?

Wednesday 30. November 2016 Seminar

Theme: National and international cooperation; how can we work together
to the benefit of our patients?

Location TRS Resource Centre for Rare Disorders, Sunnaas Rehabilitation Hospital, Nesodden

Chair: MD Nina Riise, TRS

09.00 Welcome, coffee and tea

09.15-09.45 HTAAD – clinical experiences from Ghent
Julie De Backer, Prof. Dr. MD
Department of Cardiology and Center for Medical Genetics, Ghent University Hospital

09.45-10.15 HTAAD – clinical experiences from Hamburg
Yskert von Kodolitsch
University Heart Center Hamburg

10.15-10.45 Discussion

10.45-11.00 Coffee/tea/fruit

11.00-11.30 Preliminary findings from The Norwegian Marfan Study
Thy Thy Vanem, PhD student
Dept. of Cardiothoracic Surgery, Oslo University Hospital

11.30-12.00 Follow up of adults and ageing in Marfan syndrome . Discussion

12.00-13.00 Lunch

13.00-14.00 Follow up of children with Marfan – consensus? Discussion

14.00 – 14.20 Conclusions and end of meeting
Nina Riise

15.00 Boat from Nesoddtangen