

To: Head of Clinic
Cc: Neurologists and other specialists in
the area of TTR-amyloidosis (TTR-FAP)

TTR-FAP* – optimizing Nordic collaboration and learning from THAOS registry

Stockholm, Sweden
17–18 October 2013

Chair: **Prof Ole Suhr**



*Transthyretin familial amyloid polyneuropathy (TTR-FAP)

This symposium has been
sponsored by Pfizer



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Introduction

TransThyRetin Familial Amyloid Polyneuropathy (TTR-FAP) is a rare disease with different clinical presentations (inter- and intraindividual variability of symptoms) and geographic distribution (endemic- and non-endemic areas).

The symposium TTR-FAP - optimizing Nordic collaboration and learning from the THAOS registry will have a broad focus on different aspects of the disease. Topics that will be covered include epidemiology, diagnostics, treatment and the THAOS-registry.

The main target groups for the meeting are neurologists and other specialists with an interest in TTR-FAP from Denmark, Finland and Sweden.

Speakers

- **Intissar Anan MD PhD**
FAP-team Umeå. Department of Public Health and Clinical Medicine, Umeå University, Umeå, Sweden
- **Henning Andersen Prof**
Neurology Clinic, Aarhus Hospital, Denmark
- **Bo-Göran Ericzon Prof**
Department of Transplantation Surgery, Karolinska University Hospital, Huddinge, Stockholm, Sweden
- **Jenni Jonasson PhD**
Clinical Genetics / Laboratory Medicine, University Hospital of Umeå, Umeå, Sweden
- **Sari Kiuru-Enari Ass Prof**
Department of Neurology, Helsinki University Central Hospital, Helsinki, Finland
- **Erik Nordh Ass Prof**
Department of Clinical Neurophysiology, Norrland University Hospital, Umeå, Sweden
- **Henning Mølgaard Prof**
Department of Cardiology, Aarhus University Hospital, Skejby, Aarhus N, Denmark
- **Violaine Planté-Bordeneuve Prof**
Department of Neurology, University Hospital Henri Mondor, Créteil, France
- **Rayomand Press MD PhD**
Neurology Clinic, Karolinska University Hospital, Huddinge, Stockholm, Sweden
- **Ole Suhr Prof**
FAP-team Umeå. Department of Public Health and Clinical Medicine, Umeå University, Umeå, Sweden
- **Per Westermark Prof**
Uppsala University; Department of Immunology, Genetics and Pathology, Sweden
- **Lars Wikström MD**
FAP-team Skellefteå. Department of Medicine, Skellefteå County Hospital, Skellefteå, Sweden
- **Jonas Wixner MD**
FAP-team Umeå. Department of Public Health and Clinical Medicine, Umeå University, Umeå, Sweden

Venue

Clarion Hotel Arlanda Airport
Tornvägen 2,
190 45 Stockholm-Arlanda
Tel: +46 (0) 8 444 18 00

The hotel is located at Stockholm-Arlanda Airport in the Sky City area. When you reach Sky City, go through the Sky Bridge, a glass corridor from Sky City leading up to the reception.



Travel arrangement

Thursday 17 October 2013

Connection according to your personal itinerary

06.05 – 06.25	Oulu – Arlanda
06.55 – 10.10	Århus – Arlanda via Köpenhamn
09.00 – 10.10	Köpenhamn – Arlanda
09.15 – 09.20	Vaasa – Arlanda
09.45 – 10.45	Umeå – Arlanda
09.45 – 10.50	Malmö – Arlanda
09.35 – 10.30	Göteborg – Arlanda
10.30 – 10.30	Helsingfors – Arlanda

Friday 18 October 2013

14.50 – 15.50	Arlanda – Göteborg
14.50 – 16.55	Arlanda – Vaasa
14.55 – 15.55	Arlanda – Umeå
16.00 – 17.05	Arlanda – Malmö
16.05 – 18.00	Arlanda – Helsingfors
16.15 – 17.25	Arlanda – Köpenhamn
16.15 – 20.00	Arlanda – Århus via Köpenhamn
16.30 – 21.00	Arlanda – Oulu via Helsingfors

Connection according to your personal itinerary

Application

Please note that the number of participants is limited.

Application, approved by the Head of Clinic, made on the attached reply card should be submitted as soon as possible but no later than **4 September 2013**. Registration is binding. You may not extend a trip for private purposes or bring accompanying persons.

Participation fee (applicable for Swedish and Danish participants only)

According to agreement between the research-based pharmaceutical industry in Sweden (LIF) and Swedish Association of Local Authorities and Regions (SKL), a participation fee will be charged (applicable for Swedish participants only) equivalent to at least half the cost of travel, food and accommodation. The participation fee is **SEK 1 392** (food and accommodation only) or **SEK 2 892** (travel, food and accommodation) per person. Travel to and from the airport/train station will not be reimbursed by Pfizer. The Head of Clinic must approve invoicing on the reply card. Reservation: price changes, due to circumstances beyond Pfizer's control or to changes in the scope of the journey, may occur.

Cancellation Terms (for all participants)

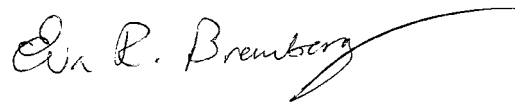
If cancelled after 17 September 2013, Pfizer will invoice the Head of Clinic the full cost of the cancellation of travel, hotel, conference fees etc. If cancellation is due to illness a medical certificate is required and must be sent to Pfizer no later than two weeks from the date of cancellation. If there is a medical certificate, no cancellation fee will be charged.

Contact information

For further information, please contact Eva Rämme Bremberg. For questions about travel arrangements please contact Camilla Olsson, CWT Meetings & Events, 08-600 85 50 or colsson@carlsonwagonlit.se

Kind regards

Pfizer AB
Specialty Care



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REPLY CARD

**TTR-FAP – optimizing Nordic collaboration
and learning from THAOS registry**

Stockholm, Sweden
17–18 October 2013



FINAL APPLICATION DATE IS 4 SEPTEMBER 2013

- ☐ Yes I would like to apply to the symposium 'TTR-FAP - optimizing Nordic collaboration and learning from THAOS registry' in Stockholm (Arlanda) 17–18 October 2013
- ☐ Yes, I agree that a list of participants is distributed at the symposium with my name and place of work included
- ☐ I will arrange and pay for my connecting trip(s)
- ☐ I need a connection trip from/to _____

Participant (Block letters as per your passport details):

Surname: _____ First name(s): _____

Place of work: _____

Work address: _____

Cell phone: _____ E-mail address: _____

Address for any mailings (for example tickets):

Address: _____

Mailing address: _____

Other information, such as allergies/special requests: _____

(Please note! Application without Head of Clinic signature is invalid)

Head of Clinic signature: _____

Surname: _____ First name(s): _____

Place of work: _____ Work address: _____

Cell phone: _____ E-mail address: _____

The **information below** regarding participation fees is applicable to **Swedish and Danish participants only** according to local regulations. To be completed by Head of Clinic or his/her representative (check only one):

- ☐ Head of Clinic will pay the participation fee **SEK 1 392** which represents at least 50 % of the cost for food and accomodation only. Pfizer AB is covering for the remaining costs.
- ☐ Head of Clinic will pay the participation fee **SEK 2 892** which represents at least 50 % of the cost for travel, food and accomodation. Pfizer AB is covering for the remaining costs.

If the final participation fee differs by more than ± 10 % from the estimated fee of invitation, the participant and the Head of Clinic will be notified and billed in accordance with the actual cost.

Address for the invoice (if different from above):

Your personal information

Pfizer store and use personal data collected from You. The data is used for sending information and materials to you in this matter. You can request information about the personal information held about You. You may at any time notify Pfizer that You want to correct errors in the data or that You oppose the continued treatment of your personal data. If you choose to leave your e-mail address with us, you agree to e-mail communication with you in this matter

REPLY PAID
SWEDEN

Pfizer AB
Att: Nina Ygfors

SVARSPOST
Kundnummer 203 624 31
191 90 Sollentuna

Frankeras ej
Pfizer AB
betalar portot
No stamp required

Preliminary Programme

Day 1: Thursday 17 October 2013

Time	Topic	Speaker
11.30–12.30	Lunch	
12.30	Welcome and Symposium overview	Ole Suhr Prof
Session 1: Epidemiology		
12.40–13.10	Characteristics of TTR-FAP in endemic areas	Chair: Ole Suhr Prof
	• Val30Met – the Swedish experience in Skellefteå vs Piteå	Intissar Anan MD PhD
13.10–15.00	The non-endemic experience	Chair: Sari Kiuru-Enari Ass Prof
	• Epidemiology and diagnostic procedures in France	Violaine Planté-Bordeneuve Prof
	• Cardiac familial TTR amyloidosis, the Danish version	Henning Mølgaard Prof
	• Looking for TTR-FAP – experiences from Finland	Sari Kiuru-Enari Ass Prof
	• Case report from Sweden, non-endemic area	Rayomand Press MD PhD

15.00–15.30	Coffee break	
Session 2: Treatment		
15.30–17.00	Treatment of TTR-FAP in 2013	Chair: TBC
	• Liver transplantation in TTR-FAP – where are we today?	Bo-Göran Ericzon Prof
	• Pharmacological treatment of TTR-FAP	Violaine Planté-Bordeneuve Prof
	• Round table discussion - treatment algorithms, patient selection	
17.00–17.15	Fruit and snacks	
Session 3: Collaboration in the area of TTR-amyloidosis		
17.15–18.30	Nordic Network	Chair: Ole Suhr Prof
	• Open discussion around opportunities, a possibility for professional exchange among specialists and/or support to referring colleagues?	
19.30	Dinner	

Preliminary Programme

Day 2: Friday 18 October 2013

Time	Topic	Speaker
07.00–08.30	Breakfast, check-out	
Session 4: Early diagnosis in TTR-FAP - obvious or impossible?		
08.30–10.00	Overcoming diagnostic challenges	Chair: Erik Nordh Ass Prof
	• Histopathology today and in the future	Per Westermark Prof
	• Genetic testing in TTR-FAP – challenges and possibilities	Jenni Jonasson PhD
	• Monitoring in peripheral neuropathies	Henning Andersen Prof
	• Neurophysiology - detection of small fibre dysfunction	Erik Nordh Ass Prof
	• Discussion – what could be done to secure as early diagnosis as possible in endemic and non-endemic areas	
10.00 –10.30	Coffee	

Session 5: THAOS registry – opportunities from a Nordic perspective		
10.30 –11.30	What can we learn from the THAOS registry?	Chair: Ole Suhr Prof
	• THAOS possibilities	Ole Suhr Prof
	• GI manifestations in TTR amyloidosis – experience from THAOS data analysis	Jonas Wixner MD
	• Discussion – what else would we like to know from the currently available data?	
Session 6: Patient perspective		
11.30 –12.30	What can we learn from the patients?	Chair: Lars Wikström MD
12.30–13.30	Lunch	
THE END		

Notes

Adresskälla. Försändelsen är utsänd med stöd av uppgifter ur Hälso- & Sjukvårdens Adressregister (HSAR), av Pfizer AB, som är anslutet till integritetsskyddsprogram för HSAR. Ytterligare information erhålls av Cegedim AB, 08-55521420 eller www.hsar.se.