

FAMILIAL AMYLOIDOSIS SUPPORT MEETING AGENDA-10-28/29-2011

WELCOME

7:30-Muriel -Get some general information, and introductions of guests

8:00- Dr. Gertz-Mayo – Amyloidosis Overview (30 minutes)

Q and A (10 minutes)

8:40- Dr. Skinner-BU – Familial Amyloidosis – Historic perspective-What is it? How is it inherited?(30 minutes)

Q and A (10 minutes)

9:20-Dr. Picken – LUMC – Familial Pathology – Familial amyloidosis – Pathologist view (20 minutes)

Q and A (10 minutes)

BREAK

10:05 - Dr. Peter James Dyck- Mayo – Peripheral Neuropathy Symptoms, Issues, Treatments(35 minutes)

Q and A (10 minutes)

10:50 - Dr. Dan Judge(Johns Hopkins) – Cardiac Symptoms and Issues(35 minutes)

Q and A (10 minutes)

11:35- Dr. Ombrello –NIH – News from The National Institute of Health (35 minutes)

Q and A (10 minutes)

LUNCH

1:30 - Zeldenrust-Mayo – TTR and Organ Transplants(35 minutes)

Q and A(10 minutes)

2:15 - Dr. Benson- Indiana(IUPUI) – Non TTR and Organ Transplants(35 minutes)

Q and A (10 minutes)

BREAK

3:00- Workshops - informal- breakaways – One Hour

(5 sessions – running concurrently- feel free to move from one to the other)

Peripheral Neuropathy (prevent, avoid, cope, treat) - Dr. Dyck

Cardiac (Symptoms, coping, treatments)– Dr. Judge and Dr. Hanna(CC)

Transplants (Yes, No, Which ones)– Dr. Zeldenrust,Dr. Berk, Dr. Picken

Genetic Issues – (Legalities and Realities) - Dr. Gertz, Dr. Skinner, Dr. Ombrello

ALA60 – (What makes us different) – Dr. Benson

BREAK

Clinical Trials

4:15 –ALNYLAM- Dr. Gollob

Q and A

4:45 -DIFLUNISAL–Dr. Berk-BU

Q and A

5:15- ISIS- Lisa Ackerman

Q and A

5:45 - PFIZER(Fold Rx)- Dr. Denis Keohane and Dan Levin and Julia Deves

BREAK FOR DINNER AND INFORMAL DISCUSSION AT HOTEL

SUNDAY-8:30AM

Dr. Gertz Moderator of Q and A with Doctor Panel with all of the doctors still in attendance.

PN

Traveling

Managing GI problems

Eye Problems

Orthostatic Hypotension

Inheritance pattern

CLOSING WORDS FROM MURIEL, LUNCH AND HOME