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. 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