Welcome/Opening Remarks
Friday morning

Jeff A. Sloan
Mayo Clinic Comprehensive Cancer Center
Rochester, MN, US

Mirjam A.G. Sprangers
Academic Medical Center, University of Amsterdam, the Netherlands

Genetic Disposition and Patient-reported Quality of Life Outcomes
Rochester, MN, February 27 – 28, 2009
We appreciate that you have travelled far...
Welcome to Rochester!
Thanks

- Mayo Foundation / CME / CCS
- North Central Cancer Treatment Group
- NCI
- Funding from Pharmaceutical Sponsors
- NCCTG/Mayo/CCS QOL Working Group
Housekeeping: Facilities

- Bathrooms
- Breaks / Meals
- Displays / Posters / Book signings
- Phones, copier, fax, messaging
- Emergency phone number: 507-284-2511
Housekeeping: miscellaneous

- Dinner tonight at Foundation House (6 blocks)
  - bus starts at 6:00 Marriott Lobby, walking maps

- Dinner tomorrow, “Winter Wonderland” Ironwood Springs Christian Ranch (30 miles)
  - buses start at 6:00 Marriott Lobby
  - buses start returning at 21:15
Friday

- Bus pickup at 6:00 outside the Marriott
- Buses will return to Marriott around 8:30
- This evening is a reward for all the work
- Networking opportunity
- Foundation House
- Professional attire
Saturday

- Bus pickup at 6:00 outside the Marriott
- Buses will return to Marriott
- This evening is a reward for all the work
- Networking opportunity
- “Winter Wonderland”
- DRESS WARMLY
Winter Wonderland Activities: Canadian Style
Sunday

- Cab, shuttle to airport, your convenience
- Complete expense record, mail back
- Include receipts, airline tickets
- Go home
Meeting Survival Facilitation

• Massage therapists: 12:30 - 13:30
• 5-minute free chair massage
• Bonaventure Room
Genetic Disposition and Patient-Reported Quality of Life Outcomes

February 26, 2009
Leighton Auditorium
Siebens Building
Mayo Clinic
Rochester, MN

Program Directors
Jeff A. Sloan, Ph.D.
Mirjam Sprangers, Ph.D.
The Challenge Before Us: Translating across Disciplines
genetic Disposition

and patient-reported
quality of life outcomes

February 26-28, 2009, Mayo Clinic, Rochester, MN
Gene-QoL Initiative: Genetic Research into Quality of Life

Overall objective
To establish strong collaborative and interdisciplinary relationships to translate and plan clinically relevant research to identify and investigate potential genes and genetic variants involved in quality of life
Gene-QOL:
An International Consortium for Genetics and Quality of Life Research

cell biology  molecular biology
behavioral genetics  pharmacogenetics
biological psychology  nursing
 genetic biostatistics  sociology
 genetic epidemiology  psychiatry
 medical psychology  oncology
 clinical psychology
Gene-QOL: An International Consortium for Genetics and Quality of Life Research
Meeting Objectives

• (1) develop a list of potential biological pathways, genes and genetic variants involved in quality of life domains, by reviewing the state of the art regarding current genetic knowledge

• (2) design a research agenda to investigate and validate those genes and genetic variants of quality of life
Outcomes

(1) A list of potential biological pathways

(2) A comprehensive list of candidate genes and genetic variants

(3) A comprehensive research agenda
   (i.e., relevant databases, ongoing genetic research that could be expanded with a quality-of-life component, and new prospective studies)

(4) An overview paper, co-authored by the entire consortium
   (i.e., summary of the list of potential biological pathways, candidate genes and genetic variants, and the research agenda)
Gene-QOL: An International Consortium for Genetics and Quality of Life Research

Relevance

The resulting knowledge will enable the exploration of new pathways of improving patient care:

- Identify patients with genetic predisposition for deficits in quality of life
- Better target specific support: effective pharmacologic and psychosocial interventions exist
- Genetically-targeted, individualized treatments for quality of life might be possible
"Your DNA test shows you're predisposed to sue doctors."
Gene-QOL:
An International Consortium for Genetics and Quality of Life Research

“Doctors will eventually use genetic patterns for several tasks -- to tell whether a cancer will spread, to predict how various therapies such as specific drugs or radiation will work, and perhaps even to see how someone's quality of life will be affected.”

(Sloan and Zhao, 2006)
What is quality of life?

Health:

A state of complete physical, social, and mental well-being, not merely the absence of disease or infirmity

WHO, 1948
WHO-based consensus of “Quality of Life”

Multi-dimensional

Physical Functioning

Social Functioning

Mental Functioning

Affected by disease/treatment
Five Outcomes Under Study

1) Negative psychological attributes (i.e. depression, anxiety, symptom distress)

2) Positive psychological attributes (i.e. happiness, life satisfaction, overall quality of life)

3) Perceived or self-rated physical health or functioning

4) Pain

5) Fatigue
WHO-based consensus of “Quality of Life”

- Physical health/functioning (team 3)
- Pain (team 4)
- Fatigue (team 5)

**Physical Functioning**

**Mental Functioning**

**Social Functioning**

- Negative psychological attributes (team 1)
- Positive psychological attributes (team 2)
GENEQOL: Faculty

Paper 1: Negative Psychological Attributes
Mirjam Sprangers, Ph.D. University of Amsterdam
Frank Baas, MD, Ph.D. University of Amsterdam
Nicholas Martin, Ph.D. University of Queensland
Miriam Mosing University of Queensland

Paper 2: Positive Psychological Attributes
Ruut Veenhoven, Ph.D. Erasmus University Rotterdam
Meike Bartels, Ph.D. VU University
Dorret Boomsma, Ph.D. VU University
Benjamin Movsas, MD Henry Ford Hospital
Gen Shinozaki, MD Mayo Clinic Rochester

Paper 3: Physical Health/Functioning
Jeff Sloan, Ph.D. Mayo Clinic Rochester
Amylou Dueck, Ph.D. Mayo Clinic Scottsdale
Donald Patrick, Ph.D. University of Washington
Ron van Noorden, Ph.D. University of Amsterdam
Ping Yang, MD, Ph.D. Mayo Clinic Rochester
GENEQOL: Faculty

Paper 4: Pain
Charles S. Cleeland, Ph.D.
Paul Klepstad, MD, Ph.D.
Christine Miaskowski, RN, Ph.D., FAAN
Nancy Pedersen, Ph.D.
Qiuling Shi, Ph.D.

U.T.M.D. Anderson Cancer Center
St. Olav University Hospital
University of California
Karolinska Institutet
U.T.M.D. Anderson Cancer Center

Paper 5: Fatigue
Michele Halyard, MD
Andrea Barsevick, Ph.D. RN, AOCN
Robert B. Diasio, MD
Marlene H. Frost, Ph.D.
Per Hall, MD, Ph.D.
Koos Zwinderman, Ph.D.

Mayo Clinic Scottsdale
Fox Chase Cancer Center
Mayo Clinic Rochester
Mayo Clinic Rochester
Karolinska Institutet
University of Amsterdam
Primary Meeting Goals

- Present conclusions of each paper
- Structured discussion
- Identify omissions
- Describe areas for future research
- Construct outline for overall paper
Meeting Format

• Each paper gets 90 minutes
  • 30 minute presentation of findings
  • 60 minute moderated Q&A discussion
Ground Rules

• Brevity is the soul of wit: 1-minute wisdom
• Disagreements are not personal
• Keep to time schedule
• We have a path already chosen, the time for going back to square one has past
• People can be nominated for massages
• We work hard, but let’s party harder!
Four Questions to Consider

• 1) Which potential biological pathways have been considered and/or shown to describe a possible genetic disposition for the indicated quality-of-life outcome?

• 2) Which genes and genetic variants have been considered and/or shown to have a potential association with the indicated quality-of-life outcome?

• 3) What datasets are available to explore the association of genes and the indicated quality-of-life outcome?

• 4) How would you design a new prospective study to explore the association of genes and the indicated quality-of-life outcome?
Goal:
Outline Overall Article

• I. Each team to write two or three points summarizing their paper in the form of SPECIFIC recommendations / guidelines

• II. Each team to write two or three items arising from their paper to be part of an agenda for future research. BE SPECIFIC
We are now on the threshold of discovery
So let’s get going!
Team 1:
Negative Psychological Attributes

Mirjam Sprangers, Ph.D.
University of Amsterdam

Frank Baas, MD, Ph.D.
University of Amsterdam

Nicholas Martin, Ph.D.
University of Queensland

Miriam Mosing
University of Queensland

Genetic Disposition and Patient-reported Quality of Life Outcomes
Rochester, MN, February 26 – 28, 2009
Team 2:
Positive Psychological Attributes

Ruut Veenhoven, Ph.D.
Erasmus University Rotterdam

Meike Bartels, Ph.D.
VU University

Dorret Boomsma, Ph.D.
VU University

Benjamin Movsas, MD
Henry Ford Hospital

Gen Shinozaki, MD
Mayo Clinic Rochester

Genetic Disposition and Patient-reported Quality of Life Outcomes
Rochester, MN, February 26 – 28, 2009
Team 4: Pain

Charles S. Cleeland, Ph.D.
U.T.M.D. Anderson Cancer Center

Paul Klepstad, MD, Ph.D.
St. Olav University Hospital

Christine Miaskowski, RN, Ph.D., FAAN
University of California

Nancy Pedersen, Ph.D.
Karolinska Institutet

Qiuling Shi, Ph.D.
U.T.M.D. Anderson Cancer Center

Genetic Disposition and Patient-reported Quality of Life Outcomes
Rochester, MN, February 26 – 28, 2009
Team 5: Fatigue

Michele Halyard, MD
Mayo Clinic Scottsdale

Andrea Barsevick, Ph.D., RN, AOCN
Fox Chase Cancer Center

Robert B. Biasio, MD
Mayo Clinic Rochester

Marlene H. Frost, Ph.D.
Mayo Clinic Rochester

Per Hall, MD, Ph.D.
Karolinska Instutet

Koos Zinderman, Ph.D.
University of Amsterdam

Genetic Disposition and Patient-reported Quality of Life Outcomes
Rochester, MN, February 26 – 28, 2009
Parting Words

• Thank you, thank you, thank you