

Rare Cancers: Challenges for Cancer Prevention and Treatment

December 10–11, 2009 • Bethesda, Maryland

Agenda

Day 1 — Thursday, December 10

The goals of this workshop are to discuss the various issues and special challenges that are associated with cancer detection, diagnostics, prognostics, and treatment of rare cancers. The objective of the workshop is to identify strategies to improve screening and early detection that may lead to prevention and better treatments for these rare but lethal cancers. This workshop will also facilitate scientific collaborations and interactions, examine new technologies, and build new research programs in this emerging field.

7:00 A.M. REGISTRATION AND CONTINENTAL BREAKFAST

8:30 A.M. Welcome — Charge of the Workshop

Stephen C. Groft, Pharm.D. — Office of Rare Diseases Research (ORDR), National Institutes of Health (NIH)

Sudhir Srivastava, M.P.H., Ph.D. — Division of Cancer Prevention (DCP), National Cancer Institute (NCI)

8:40 A.M. Cross-Cutting Issues Related to Rare Cancers – Introduction

Anna Barker, Ph.D. — NCI

9:00 A.M. Early Detection of Rare but Lethal Cancers

Sudhir Srivastava, M.P.H., Ph.D. — DCP, NCI

Stephen C. Groft, Pharm.D. — ORDR, NIH

9:40 A.M. Deadly Cancers: A Patient and Policy Perspective

Megan Gordon Don, M.H.S. — Pancreatic Cancer Action Network

10:00 A.M. Surveillance Epidemiology and End Results (SEER) Data Related to Rare and Lethal Cancers

Brenda K. Edwards, Ph.D. — Surveillance Research Program, NCI

10:25 A.M. BREAK

10:40 A.M. Collaborations (International Partners)/Access to Patient Populations and Biospecimen Collection

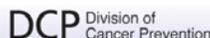
Jim B. Vaught, Ph.D. — Office of Biorepositories and Biospecimen Research, NCI

11:05 A.M. Rare Cancers of Unknown Etiology, Poorly Understood

David Sidransky, M.D. — Johns Hopkins University School of Medicine

11:50 A.M. Role of Pharmaceutical Industry in Drug Development

Sol J. Barer, Ph.D. — Celgene Corporation



12:15 P.M. WORKING LUNCH AND KEYNOTE SPEAKER

Ellen V. Sigal, Ph.D. — Friends of Cancer Research

1:15 P.M. Studies with Animal Models

Charles Keller, M.D. — University of Texas Health Science Center at San Antonio

1:40 P.M. Involvement of Patient Advocacy Groups for Rare Cancers

Josh Sommer — Chordoma Foundation

2:00 P.M. BREAKOUT GROUPS (CONCURRENT SESSIONS WITH A BREAK AT 3:30 P.M.)

Group A. Building a Knowledge-Base: Biology, Epidemiology, and Etiology

Moderators: *Dean E. Brenner*, M.D. — University of Michigan and *Gloria Petersen*, Ph.D. — Mayo Clinic

- Kidney and Other Rare Cancers
W. Marston Linehan, M.D. — NCI
- Rare Cancers Genetic Predisposition and Etiology (hereditary predisposition to colorectal cancer)
Henry T. Lynch, M.D. — Creighton University School of Medicine
- Kidney and Bladder Cancer: Biology and Transformational Approach (TCGA-like) to Molecular Diagnosis (tentative)
Paul Cairns, Ph.D. — Fox Chase Cancer Center
- New Biomarkers and New Drug Targets in Nasopharyngeal Carcinoma (NPC)
Edwin P. Hui, M.D. — The Chinese University of Hong Kong
- Studies with Animal Models (model of gallbladder cancer)
Kaoru Kiguchi, M.D., Ph.D. — University of Texas MD Anderson Cancer Center

Discussants: *Stephen J. Meltzer*, M.D. — Johns Hopkins University School of Medicine; *David Sidransky*, M.D. — Johns Hopkins University School of Medicine; *Charles Keller*, M.D. — University of Texas Health Science Center at San Antonio; and presenters and all other participants

Facilitators: *Jo Ann Rinaudo*, Ph.D. — Cancer Biomarkers Research Group, NCI and *Lata S. Nerurkar*, Ph.D. — ORDR, NIH

Group B. Facilitating Clinical Studies in Rare Cancers

Moderators: *Sanford A. Stass*, M.D. — University of Maryland School of Medicine and *Ian M. Thompson*, M.D. — University of Texas Health Science Center at San Antonio

- Clinical and Molecular Stratification of Liver Cancer
Xin W. Wang, Ph.D. — NCI
- Role of the Cooperative Groups in Rare Cancers: Challenges and Opportunities
Edward L. Trimble, M.D. — Cancer Therapy Evaluation Program (CTEP), NCI
- Collaborations (International Partners) /Access to Patient Populations and Biospecimen Collection
Nagahide Matsubara, M.D., Ph.D. — Hyogo College of Medicine, Japan (GI cancer)
Sunil Sudarshan, M.D. — University of Texas Health Science Center at San Antonio (renal cancer – biospecimens collection/sharing)
- Involvement of Patient Advocacy Groups for Rare Cancers
Jeffrey A. Kaufman — Adenoid Cystic Carcinoma Research Foundation

Group B. Facilitating Clinical Studies in Rare Cancers (continued)

- Role of Pharmaceutical Industry in Drug Development for Rare Cancers
Anne Marie M. Finley, M.S., R.A.C. — Celgene Corporation
- Using Biostatistical Approaches to Analyzing Clinical Trials in Small Numbers of Patients
Ming T. Tan, Ph.D. — University of Maryland Greenebaum Cancer Center and University of Maryland School of Medicine
- Approaches for Therapy of Leukemia in the Elderly and its Application to Therapy of Other Cancers in the Elderly
Emil J. Freireich, M.D. — University of Texas MD Anderson Cancer Center
- Developing Products for Rare Diseases
Timothy R. Coté, M.D., M.P.H. — Office of Orphan Products Development (OOPD), Food and Drug Administration (FDA)

Discussants: *Maria M. Chan, Ph.D.* — FDA; *Marna O. Davis* — Fibrolamellar Cancer Foundation; *Kathleen Brown, M.P.A., C.A.E.* — Lymphoma Research Foundation; *Josh Sommer* — Chordoma Foundation; *Sarah Wise* — Kidney Cancer Association; *Anne Marie M. Finley, M.S., R.A.C.* — Celgene Corporation; *Jim B. Vaught, Ph.D.* — NCI; and presenters and all other participants

Facilitators: *David J. Eckstein, Ph.D.* — ORDR, NIH and *Rashmi Gopal-Srivastava, Ph.D.* — ORDR, NIH

Group C. Development of New Detection, Prevention Methods/Strategies, and Therapies

Moderators: *Harvey I. Pass, M.D.* — New York University Langone Medical Center and *Kojo S.J. Elenitoba-Johnson, M.D.* — University of Michigan

- Detecting and Treating Rare Cancers
Howard A. Fine, M.D. — Neuro-Oncology Branch, NCI
- Utilization of Technologies, Molecular Diagnostics
Kevin Halling, M.D., Ph.D. — Mayo Clinic
Kojo S.J. Elenitoba-Johnson, M.D. — University of Michigan
- Biomarkers for Early Detection of Childhood Sarcomas and Mesothelioma
Frederic G. Barr, M.D., Ph.D. — University of Pennsylvania School of Medicine
Harvey I. Pass, M.D. — New York University Langone Medical Center
Jeffrey A. Toretsky, M.D. — Lombardi Comprehensive Cancer Center, Georgetown University

Discussants: *Samir M. Hanash, M.D., Ph.D.* — Fred Hutchinson Cancer Research Center; *Kevin Halling, M.D., Ph.D.* — Mayo Clinic; *Kojo S.J. Elenitoba-Johnson, M.D.* — University of Michigan; *Frederic G. Barr, M.D., Ph.D.* — University of Pennsylvania School of Medicine; *Harvey I. Pass, M.D.* — New York University Langone Medical Center; and presenters and all other participants

Facilitators: *Lynn K. Sorbara, Ph.D.* — DCP, NCI and *John Ferguson, M.D.* — ORDR, NIH

6:00 P.M. ADJOURN

7:00 P.M. SUMMARY WRITING FOR BREAKOUT GROUPS/FIRST DAY WRAP-UP

Closed session for moderators, discussants, presenters, and NIH program staff

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Day 2 — Friday, December 11

- 7:30 A.M. REGISTRATION AND CONTINENTAL BREAKFAST**
- 8:30 A.M. Rare Cancer**
Rick Ally — Former Aide to United States Senator Edward M. Kennedy Committee on Health, Education, Labor and Pensions (HELP)
Gary D. Hammer, M.D., Ph.D. — University of Michigan
Martin M. Makary, M.D., M.P.H. — Johns Hopkins University
- 9:30 A.M. Reconvene Breakout Groups to Discuss Synthesized Summaries and Concurrence**
- 10:30 A.M. Summaries from Breakout Groups (30 minutes each with panel discussion/comments from the floor)**
Group A. Building a Knowledge-Base: Biology, Epidemiology, and Etiology
Group B. Facilitating Clinical Studies in Rare Cancers
Group C. Development of New Detection, Prevention Methods/Strategies, and Therapies
- 12:00 P.M. Closing Remarks**
Sudhir Srivastava, M.P.H., Ph.D. — DCP, NCI
- 12:30 P.M. ADJOURN**



DCP Division of Cancer Prevention

