



PATIENT REGISTRIES: An Innovative Tool for Advancing Clinical and Translational Research

Sponsored by the Arizona Biomedical Research Commission and
Arizona Hospital and Healthcare Association

Program Agenda

- 8:00 – 9:00 a.m.** **Registration and Networking Breakfast**
- 9:00 – 9:15 a.m.** **Welcome and Introductions**
- 9:15 – 10:45 a.m.** **The Basics: How to Create and Operate Patient Registries for Clinical Research**
Panel: A discussion of setting goals for the registry, database creation, patient outreach and interaction, information flow to and from patient
 Ron Christensen, MD, President, Registrat
 Shahram Partovi, MD, Founder, EmergeMD, Catholic Healthcare West
 Director of Biomedical Informatics
 Pierre Tariot, MD, Banner Alzheimer’s Institute and Director of the
 Arizona Alzheimer’s Consortium “CORE”
- 10:45 – 11:00 a.m.** **Break**
- 11:00 – 12:30 p.m.** **Legal Requirements for Patient Registries: Informed Consent, HIPAA Privacy, and Data Ownership**
Panel: A discussion of the legal requirements for establishing and operating clinical research registries
 Kristen Rosati, JD, Partner, Coppersmith Gordon Schermer & Brockelman PLC
 John Mills, JD, MD, Legal Counsel, Mayo Clinic
 Rachel Nosowsky, JD, Assistant General Counsel, University of Michigan
- 12:30 – 1:15 p.m.** **Lunch**
- 1:15 – 1:45 p.m.** **Keynote: A Look to the Future of Health Information Exchange in Arizona and its Support of Research**
 Anthony Rodgers, Director of the Arizona Health Care Cost Containment System
- 1:45 – 2:45 p.m.** **Leveraging Existing Patient Information for Clinical Research Registries: Arizona Resources**
 William Johnson, PhD, Arizona State University, Center for Health Information Research – Building on Arizona HealthQuery
 Barbara Kavanagh, MSW, Founder and President –The Arizona Myeloma Network
 Kay Kays, Patient Advocates In Research (PAIR), Co-Founder: AzMN Tissue Donor Awareness Project (TDAP) – The Role of Patient Advocates
- 2:45 – 3:00 p.m.** **Wrap Up and Next Steps**