

Health Advocates in Research: A Participatory Conference

The Health Advocacy Program at Sarah Lawrence College invites advocates whose current or future work involves research advocacy to attend this day-long conference dedicated to initiating dialogue and fostering alliances. Together, we will consider these important questions:

How do we—and how should we—participate, as advocates, in research?

What ethical principles should guide our participation in research?

In recent years health advocates have focused increasing attention on scientific research that embodies promises of improved health, but also risks of human experimentation. Advocates are now working on research-related issues both from within and from outside the health care system—in disease-specific groups and clinical settings, with research organizations, the media, oversight agencies and local communities. Health advocates are using a range of strategies to be effective in the research arena: formulating/reformulating research questions, designing/redesigning studies, insuring informed consent, monitoring human subjects' protections, increasing public accountability, and finding more effective ways to safeguard research subjects and to educate patients, consumers and the general public.

Themes and issues of the conference include:

- minority participation in both research advocacy and clinical trials
- ethics and conflicts of interest—particularly with respect to corporate and institutional funding
- principles of truth-telling and transparency in advocacy in research: how advocates influence research at each stage of the process
- cooperation and competition among advocacy groups
- responsibilities of advocacy groups to their constituencies and to society at large.

Throughout the day, we will explore the relationship of research advocacy to the research establishment, to other advocacy groups and to the public.

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Office of Graduate Studies
Health Advocacy Program
1 Mead Way
Bronxville, NY 10708-5999

www.sarahlawrence.edu/advocates-research

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Health Advocacy Graduate Program

Health Advocates in Research

A Participatory Conference

**January 14, 2005
Bronxville, NY**

Health **25** Years
Program

www.sarahlawrence.edu/advocates-research

Health Advocates in Research

“To deliberately inject a poison of known high degree of virulency into a human being, unless you obtain that man’s sanction, is not ridiculous, it is criminal.”

— Sir William Osler, 1898

The conference day has been designed to maximize active engagement. Participants will gather as a whole at plenary sessions, and then break into smaller working groups to focus on specific questions and tasks. A closing session will examine the day’s work, highlight linkages and propel us toward collaborative next steps.

Conference Schedule

8:00 a.m. Sign-in; Breakfast

8:45 a.m. Framing of the Day: major themes, strengths, challenges and issues in research advocacy today

From Experience to Advocacy: an introductory session

9:45 a.m. Plenary Panel I—Models of Advocacy in Research: an exploration of the many approaches to research advocacy and an examination of their commonalities and differences

Breakout Group Discussion, Session I: How do we evaluate the effectiveness of various models of research advocacy? Where are the strengths, weaknesses, gaps and overlaps? What accounts for differences in approaches and effectiveness?

12:30 p.m. Networking Lunch: a time for less formal discussion and interchange

1:30 p.m. Plenary Panel II—Ethics of Research in Advocacy: an exploration of the ethical issues that confound us, and the principles that should guide us

Breakout Group Discussion, Session II: self-reflection, formulation of principles and plans for on-going work

4:30 p.m. Pulling It All Together: reporting back from breakout sessions and plans for the future

5:30-7:00 p.m. Reception: refreshments and conversation

Speakers and Facilitators

- **Sallie Bernard**, *Executive Director*, Coalition for Safe Minds; *President*, ARC Research; *Executive Director*, New Jersey Cure Autism Now
- **Deborah Collyar**, *President*, Patient Advocates In Research and *Program Director*, SPORE Patient Advocate/Research Team Program
- **Gwen Darien**, *Director*, Department of Survivor and Patient Advocacy, American Association for Cancer Research*
- **Kay Dickersin**, *Professor*, Department of Community Health and *Director*, U.S. Cochrane Center, Brown University
- **Rebecca Dresser**, *Professor of Law and Ethics in Medicine*, Washington University School of Law*
- **Paul Gelsing**, *Vice President*, Citizens for Responsible Care and Research (CIRCARE)
- **Rachel Grob**, *Associate Dean of Graduate Studies* and *Faculty*, Health Advocacy Program, Sarah Lawrence College**
- **Joyce Hunter**, *Director*, Community Liaison Program, HIV Center for Clinical and Behavioral Studies and *Principal Investigator*, Working It Out Project
- **Marsha Hurst**, *Director*, Health Advocacy Program, Sarah Lawrence College*
- **Ngina Lythcott**, *Vice Dean and Dean of Students*, Mailman School of Public Health, Columbia University*
- **Abbey Meyers**, *President*, National Organization for Rare Disorders (NORD)*
- **Karen Joy Miller**, *Founder and President*, Huntington Breast Cancer Action Coalition
- **Jane Nadel**, *Consumer Coalition Coordinator*, U.S. Cochrane Center, Brown University**
- **Maryann Napoli**, *Associate Director*, Center for Medical Consumers*
- **Barbara Seaman**, Women’s health advocate, journalist and author; *Co-Founder*, National Women’s Health Network
- **Jane Baker Segelken**, Breast Cancer Advocate and Health Advocacy Program student*
- **Adil Shamoo**, *Professor*, University of Maryland School of Medicine; *Co-Founder*, Citizens for Responsible Care and Research*
- **Susan Matsuko Shinagawa**, *Community Director*, Asian American Network for Cancer Awareness, Research and Training; *Co-Founder and Co-Coordinator*, Asian Pacific Islander National Cancer Survivors Network
- **Sharon Terry**, *President and CEO*, Genetic Alliance, Inc. and *Founding CEO*, PXE International

Health Advocacy faculty who will act as facilitators include:

- **Alice Herb** (Ethics and Advocacy)
- **Margaret Keller** (Health Law)
- **Terry Mizrahi** (Community Health Advocacy)
- **Constance Peterson** (Models of Advocacy: Theory and Practice)*
- **Laura Weil** (Models of Advocacy: Theory and Practice)*

Conference organizers:

- **Lois McCourt**, *Conference Associate*, Health Advocacy graduate student
- **Akiko Takano**, *Conference Coordinator*
- **Ricka Wolman**, *Public Health Consultant*

* Conference Planning Committee Member
+ Health Advocacy Program Graduate

To register, please fill out the enclosed registration form and return it with the \$75 registration fee to Sarah Lawrence College, Health Advocacy Program, 1 Mead Way, Bronxville, NY 10708.

Health Advocacy at Sarah Lawrence College

The Health Advocacy Program carefully balances a stimulating educational experience with practical, career-oriented training. The interdisciplinary core course focuses on the theory and practice of health advocacy, and courses in the humanities, sciences and social sciences explore advocacy from a variety of disciplinary perspectives. Our accomplished faculty comes from Sarah Lawrence, other academic institutions and the health care professions. Students are strongly encouraged to follow their own interests and are advised to use the three required field placements to explore advocacy in different arenas.

Health Advocacy in Practice

- Patient advocates and patient representatives help people navigate the health care system, overcome barriers to care, protect their rights as patients and make better health care decisions
- Mediators work collaboratively to resolve conflicts and facilitate change
- Educators, ombudsmen and health information specialists educate and empower patients and the general public
- Policy advocates work in government or private organizations
- Community advocates strengthen neighborhoods and communities, forge public/private partnerships, and promote health and wellness

For more information or to register, go to www.sarahlawrence.edu/advocates-research, or call us at (914) 395-2371.