



FALL 2011



Greetings from the Co-Directors

As the fall turns to winter, we reflect on our first year and look ahead to new horizons. With the generous support of Dean Woolliscroft, the Departments of Internal Medicine and Psychiatry, as well as the Ann Arbor VA, CBSSM is establishing itself as a vital force, both locally and nationally.

CBSSM is emerging as a leading research center of health communication, decision-making, and bioethics. Investigators are conducting research on topics such as the use of decision aids in understanding treatment risk, patient-provider communication, and topics in bioethics such as informed consent, engaging communities in setting research priorities, and the ethics of resuscitation.

CBSSM researchers are remarkably productive, maintaining a highly visible presence at national meetings, including the Society for Medical Decision Making and the American Society for Bioethics and Humanities.

The training of future researchers is a core goal of CBSSM. To that end, CBSSM offers fellowships to post-doctoral investigators each year. Current post-doctoral fellows Laura Scherer and Melissa Constantine contribute to ongoing CBSSM research projects, and are establishing their own research

agendas. CBSSM is currently accepting fellowship applications for 2012-13.

CBSSM also focuses on educational topics. Ray De Vries has been reviewing the medical education curriculum, focusing on bioethics, decision making, and health communication. He is organizing "Pizza and Ethics" sessions for medical students, facilitated by CBSSM faculty. CBSSM faculty are involved in designing and teaching M2 elective courses in the medical curriculum.

CBSSM is committed to promoting policy discussions and public outreach activities by sponsoring various events, such as the Bishop Lecture in Bioethics and its biweekly seminar series. CBSSM also sponsors talks by nationally recognized speakers on a variety of subjects.

Finally, CBSSM supports faculty development by making available skilled research staff support to assist with project development and execution. CBSSM staff members have expertise in a variety of areas.

If you haven't had an opportunity to attend one of our events or to find a way to get involved, we hope you will be able to do so soon!

Angela Fagerlin, PhD
Co-Director

Scott Kim, MD, PhD
Co-Director

Nancy Adair Birk, PhD
Manager

Sandra Moing
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CBSSM is a joint program sponsored by the University of Michigan Medical School and the Ann Arbor VA.

Working Groups at CBSSM

Working group meetings provide an opportunity for investigators to receive feedback on research proposals, drafts of papers, grant applications, or any other aspects of projects at any stage of development.

The **Program for Informed Communication in Health Decision Making (PIHCD)** working group meets weekly throughout the year to explore topics related to understanding and improving patient decision making about medical issues. For more information and to be added to the email list for this research group, contact Nicole Exe at nexe@umich.edu.

The **Bioethics Working Group (BWG)** meets monthly throughout the year to provide a forum for project-focused discussions with an emphasis on bioethics. The goal is to provide a productive and supportive intellectual milieu for anyone with bioethics-related projects. For more information and to be added to the email group, contact Kerry Ryan at kryanz@umich.edu.

For more information about CBSSM working groups, see www.cbssm.org/research_groups.

CBSSM Representation at National Meetings

Byrne MM, Studts JL, Schmitz S, Vinard A, Gonzalez M, D'Almeida H, Bauza C, Whitehead N, Stablefood S, **Fagerlin A**. Minority cancer survivors' perceptions and experience with cancer clinical trials participation. Poster presentation, 2011 SMDM Annual Meeting.

Fagerlin A, Holmes-Rovner M, Knight S, Ling B, Alexander S, Tulsky J, Rovner D, Tobi JE, **Kahn VC**, Ubel PA. Literacy and numeracy in veterans and their impact on cancer treatment perceptions and anxiety. Poster presentation, 2011 SMDM Annual Meeting.

Fuhrel-Forbis A, Korfage IJ, Ubel PA, Smith DM, **Zikmund-Fisher BJ**, McClure J, Greene S, Stark A, Alford S, Pitsch RK, Derry H, Dillard A, **Fagerlin A**. Informed decision making about breast cancer chemoprevention: RCT of an online decision aid intervention. Oral presentation, 2011 SMDM Annual Meeting.

Hawley ST, Witteman HO, Fuhrel-Forbis A, Holmberg C, Ubel PA, **Fagerlin A**. Preferences for breast cancer chemoprevention. Oral presentation, 2011 SMDM Annual Meeting.

CBSSM investigators were very visible at the 33rd annual meeting of the Society of Medical Decision Making (SMDM), Chicago, October 22-26, 2011.

Scherer LD, Dillard AJ, Ubel PA, Smith DM, Greene SM, McClure JB, Hensley Alford S, **Fagerlin A**. Anxiety as an impetus for action: On the relative influence of breast cancer risk and breast cancer anxiety on chemoprevention decisions. Oral presentation, 2011 SMDM Annual Meeting.

Scherer LD, Ubel PA, Holmes-Rovner M, Knight S, Alexander S, Ling B, Tulsky J, **Fagerlin A**. Litera-

cy and irrational decisions: Bias from beliefs, not from comprehension. Oral presentation, 2011 SMDM Annual Meeting.

Shaffer VA, Hulseley L, **Zikmund-Fisher BJ**. The effect of narrative content and emotional valence on decision about treatments for early stage breast cancer. Oral presentation, 2011 SMDM Annual Meeting.

Witteman HO, Zikmund-Fisher BJ, Waters EA, Gavaruzzi T, **Fagerlin A**. Integers are better: Adding decimals to risk estimates makes them less believable and harder to remember. Oral presentation, 2011 SMDM Annual Meeting.

Zikmund-Fisher BJ, Witteman H, Dickson M, Halm EA. If I'm not high risk, then that's not my risk: Tailoring estimates for low-risk patients may undermine perceived relevance. Poster presentation, 2011 SMDM Annual Meeting.

CBSSM Visiting Scholar Gina Bravo, PhD



CBSSM is pleased to welcome visiting scholar Gina Bravo to Ann Arbor for the 2011-12 academic year.

Dr. Bravo is Professor of Public Health, at the Research Centre on Aging, University of Sherbrooke in Québec.

Dr. Bravo earned a PhD in Mathematics and teaches research methods and statistics at the University of Sherbrooke. She served previously as chair of a Research Ethics Board, the Canadian equivalent of an IRB. Her research focuses on obtaining consent for participation in research from elderly individuals who lack the capacity to give consent, as well as advance directives for research.

During her sabbatical at CBSSM, Dr. Bravo plans to analyze data she collected recently on factors that influence participation in research and what investigators really do when subjects lack the capacity to give consent for research. She is also considering conducting an analysis of Health and Retirement Study data, and is planning to write a grant to examine the long-term effects of advance directives.

Dr. Bravo is accompanied by her husband, Pierre Yves, who is a retired Professor of Mathematics and Dean. They love Ann Arbor, finding it to be a beautiful, friendly city that is alive and youthful. They enjoy visiting local restaurants, museums, and musical venues. Pierre Yves is a cellist in the Life Sciences Orchestra at U-M. Welcome to CBSSM!

New CBSSM Postdoc Melissa Constantine, PhD

Melissa Constantine, PhD, has come to CBSSM to learn to apply her skills and experience in measurement, methods and policy in empirical research on ethics-related issues. Her research interest is focused on the application of social theory to model the clinical medical experience, specifically the social forces influencing routinization of genetic screening and testing in populations and the ethical implications of screening programs. She is particularly interested in prenatal and preconception genetic screening. Scott Kim and Ray De Vries are her mentors.

Dr. Constantine likes to get back to Minnesota to spend time with her son, and she is his #1 sled hockey fan. She spends eight months willing the

Minnesota Wild to a Cup and the other four months strategizing how they will win it the following year (the Red Wings are her #2 team).

Otherwise, Dr. Constantine loves to cycle and competes in a few races each year. She enjoys skiing and also training and pushing/ challenging herself physically. Friends, pets, cooking and eating, and the ocean are high on her list as well.



Research Spotlight

Naomi Laventhal, MD

Naomi Laventhal, MD, together with Director of the Division of Neonatal-Perinatal Medicine John Barks, MD, and CBSSM Co-director Scott Kim, MD, PhD, is currently conducting a study entitled, “Innovative therapies in the newborn intensive care unit: The ethics of off-label use of therapeutic hypothermia.” Responding to the desire of neonatologists to better understand treatments for patients at risk for poor outcomes, Dr. Laventhal is exploring the case of therapeutic hypothermia (TH) for hypoxic-ischemic encephalopathy (HIE), a therapy with demonstrated efficacy for full-term infants in reducing death and disability, but unproven efficacy in preterm infants. Although guidelines currently advise against off-label use, anecdotal evidence suggests off-label TH use may be common in preterm infants.

The study, which is descriptive, aims to evaluate the self-reported practices of neonatologists to determine whether and how standard and off-label TH is being used in newborn intensive care units around the country, and to determine whether individual experience with TH or clinical practice setting appears to influence these practices. To achieve this goal, electronic surveys have been sent to members of the American Academy of Pediatrics Section on Neonatal-Perinatal Medicine. Roughly 550 completed surveys have been received, with data collection ongoing.

Preliminary results suggest that therapeutic hypothermia is being used by neonatologists beyond the scope of existing recommendations, but that there is a strong interest in further scientific evaluation of the safety and benefit in these circumstances. Dr. Laventhal anticipates that the results of this study will be fully analyzed in the spring of 2012.



Dr. Laventhal is a Clinical Lecturer in Pediatrics and Communicable Diseases in the Division of Neonatal-Perinatal Medicine.

CBSSM Selected Faculty Highlights 2011-12

Angie Fagerlin was featured recently on the CBS News website in a slideshow on making decisions about cancer treatment. CBS highlighted 10 secrets of better cancer decision-making, taken from a paper she recently published with **Brian Zikmund-Fisher** and **Peter Ubel** in the *Journal of the National Cancer Institute*.

Scott Kim wrote a recent paper appearing in *Nature Reviews Neurology* on the ethics of informed consent in Alzheimer disease research, focusing on autonomy and authenticity. In the paper, he reviews the empirical research involving people with decisional impairment, highlighting what has been learned from those studies, as well as their policy implications.

Kathryn Moseley and **Naomi Laventhal** (with several other colleagues) will be teaching a bioethics elective for medical students at U-M this fall titled, "Pediatric Ethics and Ethics Consultation."

Beth Tarini was selected to serve as co-medical director of a Genetics in Primary Care Institute grant awarded to the American Academic of Pediatrics. The three year award is provided by the Health Resources and Services Administration Maternal and Child Health Bureau.

Brian Zikmund-Fisher is PI of a National Institute of Environmental Health Sciences (NIEHS)-funded study that will explore the mental conceptualizations of risk of dioxin-like compounds among residents in Midland/Saginaw, MI, who live in areas that have been exposed to dioxin.

Susan Goold received an R01 award to develop and evaluate a software tool to engage minority and underserved communities in setting clinical and translational research funding priorities.

Darin Zahuranec received a K23 award that aims to examine how physicians and family members make end-of-life decisions for patients who have suffered a severe stroke.

Joel Howell, **Ray De Vries**, and **Andrew Bar-nosky** participated in a two-day conference on the UM campus in April entitled, "Where religion, policy, and bioethics meet: An interdisciplinary conference on Islamic bioethics and end-of-life care."

Kathryn Moseley was recently interviewed by A2Ethics.org. Dr. Moseley spoke about the obstacles and opportunities in building trusting relationships between parents, children, and pediatricians. See a2ethics.org/node/875 to download the interview as an audiofile.

Ray De Vries began a joint appointment as Professor of Midwifery Science at Maastricht University in the Netherlands last November. See his CBSSM webpage to view his inaugural address at <http://cbssm.org/people/58>.

With CBSSM alumni **Peter Ubel** and **Andrea Angott**, **Brian Zikmund-Fisher** recently published a paper in the *Archives of Internal Medicine* exploring the ways physicians' decisions are influenced by the act of making a recommendation. They found the act of making a recommendation changed the ways that physicians think about medical choices.

With CBSSM investigator **Ed Goldman**, **Joel Howell** published a paper on newborn screening and dried blood spots for research in *Genetics in Medicine*.

Angela Fagerlin spoke with the *Chicago Tribune* about how patients can make sense of treatment risks when talking with their doctors.

CBSSM Events 2011-12

Michael Siegrist/Julie Downs Talk September 22, 2011

Sponsored by CBSSM and the Decision Consortium, Michael Siegrist of ETH Zurich gave a talk entitled, "Risk communication: The importance of numeracy." Julie Downs of Carnegie Mellon University presented a talk entitled, "Overcompensation undermines strategies for promoting healthier eating behavior." Both were featured speakers at the Risk Science Center's Bernstein Symposium.

Open Wound Book Tour

Dr. Jason Karlawish October 20, 2011

Co-sponsored with the **Center for the History of Medicine** and the **University of Michigan Press**, **Dr. Jason Karlawish** of the University of Pennsylvania discussed his new novel, "Open wound: The tragic obsession of Dr. William Beaumont." It is a fictional account of the complex relationship between Dr. Beaumont and his French Canadian patient and research subject.

Ethical Imperialism Talk, Panel

Dr. Zachary Schrag Wednesday, February 1, 2012

In light of OHRP's Advance Notice of Proposed Rule Making suggesting considerable modifications to human subject regulations, **Dr. Zachary Schrag** of George Mason University will discuss his 2010 book, "Ethical Imperialism: Institutional Review Boards and the Social Sciences, 1965-2009." Schrag argues that social science researchers were excluded from rule making, resulting in university ethics panels routinely impeding the work of scholars in those fields. Following, several U-M faculty will participate in a panel discussion of the IRB's influence on social science research. The event is in **Palmer Commons, Great Lakes South** at **3 pm**.

2012 Bishop Lecture in Bioethics, Bioethics Colloquium

Plans are currently under way for the Bishop Lecture in Bioethics and the Bioethics Colloquium, tentatively planned for May 2012. Please watch www.cbssm.org for more details.

Dr. Amy McGuire Baylor University March 22, 2012

Amy McGuire, JD, PhD, is Associate Director for Research in the Center for Medical Ethics and Health Policy, Baylor College of Medicine. She will be a featured presenter at a CBSSM seminar on March 22 at 3:30 pm. Please watch www.cbssm.org for more details about her talk.

CBSSM Seminar Series 2011-12

Twice-monthly seminars are sponsored by CBSSM on a variety of topics. Seminars are generally scheduled for the first Wednesday and third Thursday of each month, at 3:30-4:45. See www.cbssm.org/events for details; send a message to nbirk@umich.edu to be added to the seminar mailing list.

Upcoming seminar dates:

December 15
January 19
February 1, 16
March 7, 22
April 4, 19
May 2, 17

Additional events are being planned for the current academic year and will be announced as information becomes available.

CBSSM Post-doctoral Fellowship Program 2012-13

CBSSM is currently soliciting applications from qualified individuals for two post-doctoral research fellow positions for the 2012-13 academic year:

Bioethics Post-Doctoral Research Fellow

Active projects in bioethics at CBSSM currently include informed consent and therapeutic misconception, surrogate decision-making, decision-making capacity for treatment and research, deliberative democratic methods in bioethics, resource allocation, and the sociology of medical ethics/bioethics, among others. Candidates' area of focus must be in bioethics, although their backgrounds may be in social or natural sciences, humanities, medicine, or law.

Decision Sciences Post-Doctoral Research Fellow

This fellowship focuses on understanding and improving the health care communication and decisions made by both patients and providers. Past post-doctoral fellows have included scholars whose research in health care communication and decision-making has been approached using theories drawn from social cognition, motivation and emotion, risk communication, ethics, and economics.

CBSSM has five broad programs that serve its research mission and fellows will usually focus on one of these areas. Please see www.cbssm.org/research to learn more.

- Program in Clinical and Research Ethics
- Program in Health Communication and Decision-Making
- Program in Medicine and Society
- Program in Health, Justice, and Community
- Program in Genomics, Health, and Society

Post-doctoral fellows are expected to collaborate on established projects and are encouraged to conduct independent research with an emphasis on study inception, manuscript writing, and applying for grants. CBSSM's resources and collaborative support enable the fellows to build their own research programs.

Salary is competitive and commensurate with experience and education. **All** requirements of the PhD or equivalent terminal degree must be completed before the post-doctoral research fellow appointment can begin. Candidates should submit a letter of research interests, reprints/preprints, CV, and three letters of recommendation by **February 1, 2012**. Application materials should be sent in electronic format to:

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New Faces at CBSSM

Daniel Connochie joined CBSSM in June 2011 as a Research Associate, working with Angie Fagerlin. Dan recently completed an undergraduate degree at Haverford College in Pennsylvania. Dan plans to pursue graduate work in social psychology.

Meghan Roney joined CBSSM in July 2011 as a Research Associate, working with Angie Fagerlin and Michael Volk. Meghan earned a bachelor's degree in psychology at U-M and an MPH at Emory University.

Melissa Constantine is CBSSM's first Bioethics Post-doctoral Fellow. Melissa earned a PhD in Health Service Research and Policy at the University of Minnesota. Scott Kim and Ray De Vries are her mentors.

Selwan Edward, who is from Iraq, will be visiting the University of Michigan this year, having recently completed his residency at Providence Hospital. Michael Volk serves as his mentor.

Hayley Getzen is a new student worker at CBSSM; she is a graduate student in the School of Public Health. **Diana Leon** is an undergraduate student majoring in psychology.



Staff Promotions

Valerie Kahn has been promoted to Research Area Specialist Intermediate. She serves as project manager for the CECCR study (Center for Excellence in Cancer Communication Research). Congratulations, Valerie!

Nicole Exe has been promoted to Research Area Specialist Intermediate. She will act as survey coordinator for investigators wishing to use Qualtrics to collect data online. Congratulations, Nicole!

Staff Departures

Sonali Parnami left CBSSM to move to California with her husband, who is taking a new position there. We miss her and wish her well in her new home.