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DECISION AID PORTFOLIO UPDATE

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NEW PROGRAMS

Acute Low Back Pain: Managing Your Pain Through Self-Care (April 2005)

Colon Cancer Screening: Deciding What's Right for You (January 2005)

Spanish Version: Is a PSA Test Right For You? (February 2005)

Living With Metastatic Breast Cancer (June 2005)

PROGRAMS IN PROGRESS

Managing Menopause (Due Fall 2005)

Depression (Due Fall 2005)

Androgen Deprivation (Due Early 2006)

Bariatric Surgery (Due late 2005)

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PROGRAM REVISIONS COMPLETED (by July 2005)

Treatment Choices for Benign Prostatic Hyperplasia (BPH):
Choosing Surgical or Non-Surgical Treatment

Treatment Choices for Coronary Artery Disease

Living with Coronary Artery Disease: Doing Your Part

Treatment Choices for Low Back Pain: Spinal Stenosis

Treatment Choices for Low Back Pain: Herniated Disc

Treatment Choices for Osteoarthritis of the Knee

PROGRAM REVISIONS IN PROGRESS

Early Stage Breast Cancer: Choosing Your Surgery

Informed Healthcare Consumer

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*"My advice to people about making a decision about having weight loss surgery is to consider all of your options very carefully. I think that it's important to talk to people that have had the surgery and to understand what kinds of aftereffects you can have from the surgery. I think that it's also important to understand that you can gain the weight back if you don't change the way that you are eating forever. You can never go back to eating the way that you have in the past. You have to make a commitment to say "I am going to continue to not eat the way I used to."
-A patient who decided not to have weight loss surgery*

OTHER CURRENT PROGRAMS***Breast Cancer:***

Early Breast Cancer– Hormone Therapy and Chemotherapy: Are They Right For You?

Breast Cancer- Ductal Carcinoma in Situ (DCIS): Choosing Your Treatment

Breast Reconstruction: Is it Right for You?

Orthopedics:

Chronic Low Back Pain: Managing Your Pain and Your Life

Treatment Choices for Hip Osteoarthritis

Reproductive:

Treatment Choices for Abnormal Uterine Bleeding

Treatment Choices for Uterine Fibroids

Ovarian Cancer–Reducing Your Risk

Prostate:

Treatment Choices for Prostate Cancer

Is a PSA Test Right for You?

General:

Peace of Mind: Personal Stories About Advance Directives

AWARDS**Award for Excellence in Research**

Dr. Annette O'Connor won the University of Ottawa's 2005 award for Excellence in Research in recognition for her work to understand and improve the decision making process for patients. The University of Ottawa, the Association of Professors of the University of Ottawa (APUO), and the University of Ottawa Alumni Association sponsor the University of Ottawa Award for Excellence in Research.

Program Awards

Living with Coronary Artery Disease:Doing Your Part has won a Silver Award in the 2005 Health and Science Communications Association (HeSCA) Media Festival. Additionally the Adjuvant and OA Hip programs were given Bronze Awards. HeSCA Media Festival awards health communications media demonstrating outstanding design and production values. The HeSCA Media Festival is judged by leading health communications professionals using criteria such as technical quality, production values and techniques, educational design, technological innovation, creativity, and craftsmanship of the media product.

Dissemination of Commonwealth

Grant Findings

"Breast Cancer Treatment Decision Making: Does the Sisterhood of Breast Cancer Transcend Culture?"

was accepted for a poster presentation at the Society for Behavioral Medicine's annual conference in Boston, April 15 and at the 3rd International Shared Decision Making Conference in Ottawa on June 15.

In addition, a paper based on this research has been accepted for publication in "Research in the Sociology of Health Care," scheduled to come out in November 2005.

The support for the research was provided by both the Foundation and a grant from the Commonwealth Fund. This team effort represented collaboration between FIMDM and our colleagues at MGH. The principal investigator, Pam Wescott, Senior Research Associate here at the Foundation headed a team which included Ellen Reifler, FIMDM, Karen Sepucha, MGH, and Elyse Park, MGH.

Disparities in health care for underserved populations have led to concern about the quality of decisions made by these patients. Our purpose in doing this research was to increase our understanding of how to help women in underserved populations make better decisions about the treatment of breast cancer. We conducted 8 focus groups with a total of 44 women from diverse populations, in four different locations, in order to evaluate our newly revised video, *Early Stage Breast Cancer: Choosing your Surgery*.

We found that individual differences were more common than differences among demographic groups. We also found that translating the video into Spanish would increase its usefulness. We concluded that this decision aid was helpful and effective in general without targeting it to specific groups and that language, more than race or ethnicity was relevant for viewers.

FIMDM STAFF NEWS

- **Karen Sepucha** and family have recently relocated to Washington, DC. Karen will continue her role as Medical Editor of the breast cancer programs and will continue to oversee the Breast Cancer Initiative and decision quality research.
- **Erin O'Rourke** has joined the Foundation as the new Research Assistant. Recently relocated to Boston from the Philadelphia area, she previously worked in research for the pharmaceutical industry. She has a B.S. in Health Studies from Georgetown University.
- **Catherine Finn** has joined the Clinical Evidence Team as a Research Associate. Prior to joining the Clinical Evidence Team at FIMDM, she worked as a research assistant in the Child Psychiatry Department at Massachusetts General Hospital, and as a research assistant at the Harvard School of Public Health. Cathy holds a B.A in Literature and Psychology and a B.S. in Mass Communications from Boston University and a Masters in Social Work from Simmons Graduate School of Social Work, where she now teaches a course in writing for research during the summer term.
- **Marlie Kovacs** moved to St. Louis in July to get married. However she will still be working with the Foundation as a consultant. Congratulations Marlie and we'll miss you!

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Staff News (continued from Page 3)

Lyn Paget, MPH joined us in August 2005 to work on several new initiatives at the Foundation. She has a BS in Health Education from the University of Massachusetts, Lowell and a Masters in Public Health from the University of California, Los Angeles. Before joining the Foundation, she served as Vice President of the Medical Outcomes Trust in Boston. In management and consultative roles, her work has concentrated in health care quality improvement, with a focus on program planning, evaluation and policy development.

I'm married to a rover, who loves to travel 'round,
 But I'm not fond of jet lag, so I prefer our own hometown.
 But one meeting that he travels to, he doesn't have to ask
 me twice—
 The countryside is beautiful, the folks are so darned nice.
 In a valley ringed by mountain peaks, crowned with sunlight
 and blue skies,
 Everywhere you turn to look, nature's treasures treat your
 eyes.
 The place is filled with history, generations have worked the
 land.
 The town is tourist-friendly—western gear to suit your brand.
 The local sport is rodeo with all that cowboy stuff—
 Bull-riding, barrel-racing—they're spirited and tough.

 Just as proud and dedicated is the crew of the Foundation;
 They'll engage your mind and reward your role with their
 heartfelt invitation.
 So gather up your families, make this site your summer
 goal—
 For nothing can compare with good times at Jackson Hole.

Jean W. Barry
 July 25, 2005

Jackson Hole Meeting

The Foundation held the second Annual Medical Editors' Meeting in Jackson Hole, Wyoming on July 25-27th. This year the focus was on integrating shared decision making into primary and specialty care sites.

50 meeting participants and their guests attended including medical editors, clinical advisors, Foundation board members, staff, and friends of the Foundation.

Presentations included panels on integrating decision aids into primary and specialty sites. Additionally, Ben Moulton from the American Society of Law, Medicine, and Ethics led a discussion on legal aspects of shared decision making and George Bennett, CEO of Health Dialogue, gave a presentation entitled "How We Are Changing Medical Care in the United States."



Cooperating Sites Funding Announced

The Foundation recently announced awards for cooperating sites for the current year. The purpose of the Cooperating Sites research awards is to fund proposals with potential that will have a significant, positive impact on engaging patients as partners with their health care providers when decisions must be made about medical tests, treatment, or management of chronic conditions. In making the decision to expand our cooperating sites, we anticipate learning from testing a range of programs and from gaining the participation of diverse populations. The following proposals were chosen on a competitive basis to receive this funding.

Allegheny General Hospital- Allegheny Center for Shared Decision Making

Allegheny General Hospital- Allegheny Center for Shared Decision Making (ACSDM) aims to offer every patient diagnosed with breast cancer the opportunity to participate actively in the decisions that affect her care through access to video and print resources and to health coaches. The ACSDM will quantify program success and deliver reports on economic outcomes, clinical outcomes, and changes in the patients' decision making process and psychosocial status.

University of Cincinnati College of Medicine

This proposal is to study the implementation and effectiveness of two shared decision making programs: "Living with Coronary Artery Disease," and "Personal Stories about Advance Directives" in a hospital-based ambulatory practice focusing primarily on issues of health literacy.

UCLA

Building on previous experiences, this site will recruit 10 community based, primary care physicians in Los Angeles County to learn more about barriers and solutions to making patient decision aids a part of routine clinical practice while serving diverse low income populations.

Arizona Cancer Center

This site proposes a study of the use of the FIMDM video decision aids for women facing decisions at different phases in their treatment of breast cancer. The study will focus on the response of Latina women to determine the feasibility and acceptability of the video materials for this population.

UCSD

UCSD builds on the experiences of the past eighteen months in understanding some of the barriers to implementation of shared decision-making in the busy primary care office to answer questions that remain as to how to incorporate decision aids into patient visits and how physicians can gain knowledge, skills, and the proper attitude to allow this process where appropriate.

The **George Bennett Fellowship** has been awarded to Jared Adams, a M.D./Ph.D. candidate at Dartmouth Medical School. The proposed research will assess the decision making needs of people with severe mental illnesses and their clinicians and create a model decision aid that meets the local needs of clients and clinicians. The grants are designed to support basic and applied research that can advance the field, and to attract scholars to the field of shared decision making in medical care.

The primary mission of the Foundation for Informed Medical Decision Making is to strengthen the role patients play in selecting treatments for their medical conditions. Medical research on practice variation indicates that patient preferences are often less important in treatment decision than factors having little to do with patients or their illnesses, such as geography, economics or supplier-induced demands. We achieve our mission via the following objectives:

- *Provide patients with the perspectives and information they need when they face decisions about medical testing and treatment.*
- *Improve the quality of decisions patients make in collaboration with their physicians*
- *Foster research to learn how best to help patients who face health care decisions.*

In a complex medical environment, where cost savings, commercial interests or professional beliefs and commitments are likely to drive medical decisions, the goal of the Foundation is to provide information that is as objective, complete and unbiased as possible. The Foundation acknowledges the right and responsibility of patients to be fully informed and to play the lead role in decisions that affect their health.