



To: Patients and colleagues  
From: Jeff Belkora  
Subject: Greetings, update, and a request from UCSF Decision Services

Best wishes for 2010 to you and your family. One of my New Year's resolutions is to send you a brief annual update about the Decision Services program at the UCSF Breast Care Center and some of my related activities:

1. The UCSF Decision Services program continues to grow and we are continually adapting our services based on feedback. We are particularly grateful to those of you who have given us your specific suggestions, complaints, requests, or compliments.
2. Decision Services has received national recognition for our innovative approach to supporting patients and our influence is expanding. Thank you to our many program participants and supporters.
3. REQUEST: If you have personal experience with Decision Services, please respond to this email (or call me) if you are willing to go "on the public record" with your story. We receive frequent requests from medical students, funders, and journalists who want to hear from you.

Please read the postscript for more details on the above topics. You can also find more information on the Decision Services website, [www.decisionservices.ucsf.edu](http://www.decisionservices.ucsf.edu), and on my public interest website, [www.jeffbelkora.com](http://www.jeffbelkora.com).

I am particularly grateful for funding and other forms of support from the Breast Care Center, the Department of Surgery, and the Institute for Health Policy Studies at UCSF. The visionary leaders of these organizations (respectively: Laura Esserman, Nancy Ascher, and Claire Brindis) have created the conditions in which our unique program is possible. We have also received key support from the Foundation for Informed Medical Decision Making, Safeway Foundation, Wells Fargo, and individual donors. As a result our programs continue to be free of charge to patients, and we have increased capacity to share our findings and know-how.

Any of us may face a family health crisis at any time. I am personally grateful to be part of a community that supports people in times of need.

Regards,

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## **POSTSCRIPT – MORE DETAILS**

You can download a PDF version of this letter at [www.jeffbelkora.com/2009ar](http://www.jeffbelkora.com/2009ar)

### **1. Program update**

Our core UCSF program is described at [www.decisionservices.ucsf.edu](http://www.decisionservices.ucsf.edu). Our premedical interns (recent college graduates working at UCSF for a year or two) connect new patients with decision aid materials (where applicable), and offer to assist (subject to our capacity) with question-listing, note-taking, and audio-recording for decision-making visits to surgeons and oncologists.

This program has grown to the point where 500 clinic visitors a year receive decision aids in the form of videos and booklets. Topics including ductal carcinoma in situ, surgery and adjuvant therapy for early stage breast cancer, reconstruction after mastectomy, and living with metastatic disease. Surveys indicate that the videos and booklets are working as intended – most patients who review them gain knowledge and express high degrees of satisfaction. Specifically, among the 35% of video/booklet recipients who respond to our surveys, scores on our knowledge quizzes increase from 50 to 81% correct, while 96% of survey respondents endorse the statement, “I would recommend this video to other people who are facing the same decision.” Some people have specific objections, concerns, or suggestions about the decision aid contents – we forward these to the producers at the Foundation for Informed Medical Decision Making and Health Dialog.

The premeds also attempt to contact all of our new patients to offer question-listing, note-taking, and audio-recording services. So far in the current program year (July to December 2009), we offered our services to 284 eligible visitors, of whom 185 (65%) accepted our offer to be added to the waitlist. We ultimately served 162 (88%) of those 185. These patients received a word-processed summary of their questions and the doctor’s answers, and an audio-recording of their appointment. On average, the premeds helped patients document an additional 12 questions that they wanted to ask their doctors but had not written down and might otherwise have forgotten. Surveys indicate that patient confidence in knowing what questions to ask increased from 6.7 to 8.1 on a scale of 0-10; that 84% of service recipients review the notes or recordings within 6 weeks; and that overall satisfaction was a median of 9 on a scale from 0 to 10.

Our intention is that patients can use our materials and services to better absorb, understand, and act upon the advice and information presented by our doctors. We are happy to report that our program seems to be having the desired effect overall. However, we are always trying to improve the efficiency and effectiveness of our program. We appreciate all the candid feedback we get from patients, doctors, clinic staff, premeds, and others. Please feel free to contact me any time with suggestions, complaints, requests, or compliments.

### **2. Recognition and Influence**

Our services are free of charge to patients thanks to a unique partnership between UCSF and the Foundation for Informed Medical Decision Making. The Foundation provides funding for our core operations, including program evaluation, while UCSF funds the field operations, including the delivery of materials and services by premedical interns under my supervision.

The partnership has an explicit goal to learn what works and what doesn't about decision support, and share our story with the rest of the world. Thanks to some public relations activities by UCSF and the Foundation, our program has recently been featured in the national media, including the Wall Street Journal, US News and World Report, and KQED radio. We have also published scientific reports of our research in academic journals such as the Journal of Clinical Oncology, Patient Education and Counseling, and the Journal of Cancer Education.

In addition, thanks to our participation in various national conferences and quality improvement initiatives, we have obtained recognition as a leading innovation from the Mayo Clinic, the US Agency for Healthcare Research and Quality, and the Institute for Operations Research and Management Science. Please visit our website [www.decisionservices.ucsf.edu](http://www.decisionservices.ucsf.edu) for relevant links.

This recognition may lead in turn to greater influence. Federal and state legislation is pending that would fund greater research and/or implementation of decision support, and I am actively engaged in outreach to policy-makers in Washington, D.C. and Sacramento.

Generally, thanks to this exposure, I am expanding my collaborations to more broadly disseminate decision support to people who need it. I am keeping my public interest website, [www.jeffbelkora.com](http://www.jeffbelkora.com), updated if you ever want or need a current summary of activities. Briefly, I am proud to be working with colleagues at BreastCancerTrials.org; the Palo Alto Medical Foundation; the Cancer Resource Centers of Mendocino County; the Cancer Support Community; Breast Cancer Connections; the Humboldt Community Breast Health Project; and others.

I am professionally devoted to the cause of involving and informing people in health care decisions, and grateful for the platform we are all building.

### **3. Volunteer opportunity for people who have received Decision Services**

You are the reason we exist. As for any service at UCSF, we protect your identity, confidentiality, and privacy. However, medical school students, funders, journalists and others are often eager to hear from one of you, the patients who received our materials and services. There is no obligation whatsoever, but if you are willing to share your story with students, funders, and journalists, please respond to this email and I will be in touch with you further to arrange a suitable contact.

As I conclude this postscript, I want to re-iterate my gratitude for being part of a community that supports people in times of need. Best wishes for 2010.