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Prophylactic mastectomy (PM), the surgical removal of a healthy breast, is a risk reduction option offered to women at increased genetic risk of breast cancer. There is limited data on the psychological effects of PM on body image, self-esteem, marital and family relationships, etc. A psychological consultation offered to women making this irreversible decision would likely improve decision-making and subsequent coping. The design of this consultation is best informed by data about physical and emotional effects of surgery from women who have had this procedure. This project aims to gather such data through taped, telephone interviews with women who had both breasts removed prophylactically (N=25), women with cancer in one breast who had both breasts removed (N=50), and women considering PM (N=50). We aim to determine 1.) emotional and interpersonal effects of PM, 2.) what women at increased risk of breast cancer anticipate the effects of PM surgery to be, and 3.) if women in both groups believe psychological consultation about PM is useful. To date, interview schedules have been completed, pilot interviews conducted and analyzed, surgeons successfully involved in patient review and permission, and **IRB** approval finalized. Subjects are now being enrolled and interviews scheduled.

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Introduction

Prophylactic mastectomy (PM), the surgical removal of a healthy breast, is a risk-reduction option offered to women at increased genetic risk of breast cancer. There is limited data on the psychological effects of PM on body image, self-esteem, marital and family relationships, etc. A psychological consultation offered to women making this irreversible decision would likely improve decision-making and subsequent coping. The design of this consultation is best informed by data about physical and emotional effects of surgery from women who have had this procedure. This project aims to gather such data through taped, telephone interviews with women who had both breasts removed prophylactically (N=25), women with cancer in one breast who had both breasts removed (N=50), and women considering PM (N=50). We aim to determine 1.) emotional and interpersonal effects of PM, 2.) what women at increased risk of breast cancer anticipate the effects of PM surgery to be, and 3.) if women in both groups believe psychological consultation about PM is useful. To date, interview schedules have been completed, pilot interviews conducted and analyzed, surgeons successfully involved in patient review and permission, and IRB approval finalized. Subjects are now being enrolled and interviews scheduled.

Body

Year 1 of this project has focused on development, piloting, and approval of the interview schedule and demographic form and preparation of the patient database representing eligible subjects in the 3 institutions where patients are being accrued. It was not anticipated that research results would be available at this point in the research, although preliminary findings from the pilot interviews and response from the surgeons whose patients are being invited are of interest.

The preparation of the interview schedule has been completed. Writing the interview questions involved review of the topic areas and generation of user-friendly open-ended main questions inviting subjects to discuss a particular area, e.g. history of their decision-making about PM, immediate surgical impact, physical and emotional recovery, body image, communication with family and physicians about PM. Following each main question, a series of graded probes were produced so that the interviewer could draw out subjects on topics not spontaneously covered. This will allow for comparison of responses between subjects. The interview contains 7 main questions and typically 5 probes to follow. A copy of the PM interview is appended to this report.

We also produced a demographic form for use with all subjects. This form allows for collection of demographic and family history data which is important for defining the sample being studied. In addition to usual questions about education, marital status, income and occupation, we are asking subjects to tell us about their medical history and that of their immediate and extended family, and about the utilization of genetic testing within their family, specifically whether there is a known BRCA1/2 mutation in their family. Because of issues about the confidentiality of genetic testing information, we requested this information carefully in ways which do not necessitate defining exactly who within the family carries the known mutation. Because of the grouping of responses, we are, however, able to tell if the relative is a first or second-degree relative, and thus,

what the risk status of the subject is likely to be. We also include a grid for reporting of the kinds of cancer which relatives of the patient have had. We adapted a version of a family history form under development by Dr. Fred Li and his colleagues here at the Dana-Farber Cancer Institute. Family history forms for genetic testing are rather challenging to develop because of the extent and depth of the information needed. (A subcommittee of the National Coalition of Health Professional Education in Genetics, for example, has been set up to try to develop a genetic family form for use by the range of professionals who are in need of such a tool.) We enclose a copy of the demographic form as approved by the DFCI/Partners Institutional Review Board.

The demographic form and Interview schedule were piloted first for readability with several women and then for content, understandability, and comprehensiveness with 5 women who had undergone prophylactic mastectomies, but were not eligible for our protocol. We were impressed by the willingness to participate in pilot interviews of women contacted through a web-based support group for women at increased genetic risk for cancer and through a local social worker at an outside hospital. We had many more potential subjects than we could use, suggesting both great interest in reporting one's experience among women who have undergone PM and, hopefully, suggesting high accrual among subjects invited to participate in the research interviews. Themes emerged from the pilot interviews which we will watch for in the research interviews. These included:

- Prophylactic mastectomy as a treatment of choice for women who had experienced Hodgkin's disease in adolescence who were treated with mantle radiation,
- Differentiation of body-image and self-esteem decline related to cancers on the "outside" (like breast cancer) and cancer on the "inside" (like Hodgkin's disease),
- Expectations that psychological consultation would be offered to talk one into or out of a decision about prophylactic surgery, rather than focusing on the appropriateness of the decision for the individual making the choice. This suggests that any offered consultation will have to be very carefully described to potential users in ways which dispel any fears of being coerced.
- A tendency by some women to downplay the reactions of partners or spouses in making the decision about PM as well as a disconnection between social support offered by sexual partners and feelings of unattractiveness and low libido among women following surgery.

Both the pilot subjects and our surgeon consultants who reviewed the interview and demographic form made minor suggestions which led to improvements of the research tools. In general, pilot subject interviews took about 40-50 minutes and subjects reported no distress in participating. In fact, 2 of the 5 subjects refused the honorarium they were offered, stating that they were just glad to contribute to research on these issues.

Pilot testing of the PM interview allowed for recognition of problems in the use of the telephone recording tape recorders which did not click or otherwise indicate the end of side one of the tape. Since transcription of interviews is the basis of the ultimate

coding of our qualitative data, it is necessary that the tapes be true records of the interview conversation. We have re-ordered recorders with a feature which makes the interviewer aware of the end of a side of the tape. We also utilized the pilot tapes to begin to obtain uniformity in interviewer style through mutual review of interviewers conducted by Drs. Patenaude and Orozco.

We have utilized our surgical and oncology consultants in many phases of the project. They reviewed our letters to the surgeons, suggested ways to approach the surgeons, and reviewed our interview and demographic forms. They advised on database development.

Development of the patient database for determining eligibility to participate was a much more challenging task than originally anticipated. Because the three hospitals involved keep separate records (despite all being part of the Partners Health Care System), and have different systems for accessing patient records (all requiring different access permission request procedures and training), it was quite complex to get and to check lists of women who had had bilateral mastectomies. Although there were procedure codes for prophylactic mastectomy in more recent years, there were no such codes in the earlier years of the decade we are studying. And there is no way short of review of some aspects of the medical record to determine if the prophylactic surgery was in the context of having a mastectomy on the other diseased breast or whether both breasts were removed prophylactically. Our revision of letters to the surgeons and to the patients based on our greater knowledge of the eligible subject population all required IRB amendment requests. It was also necessary for us to write and await approval for amendments which modified our patient recruitment for surgeons who had left the hospital for another system or who had retired. Because of changes in the structure of our IRB and their policies, all such alterations required review by the full committee rather then the previous policy of quick, administrative approval for non-essential changes. Full review often meant a 2-4 week lag before an amendment was approved, which sometimes slowed our ability to advance to the next stage of the research.

On the other hand, surgeons proved ultimately to be very willing to review the patient lists we sent and to offer permission for their patients to be invited. Over 90% of the 36 surgeons we wrote or spoke to returned their patient lists with approvals for most or all of their patients. Patients were typically omitted because they had had bilateral cancer and thus, no prophylactic mastectomy. One surgeon wrote a long letter explaining that he had a lack of trust in psychologists due to earlier unethical behavior on the part of a psychologist he allowed to observe his operating room. Two other surgeons have promised to provide data, but have cited busy schedules for not having yet completed the forms. In several cases, multiple sets of packets of surgeon request and patient permission letters had to be sent to achieve this end. Several surgeons suggested names of additional patients who are eligible subjects for our research who had for one reason or another been omitted from our previous lists.

A final hurdle is the agreement we made with another researcher who is doing a questionnaire study of different issues (mostly physical functioning) in patients who had

bilateral mastectomies that we would allow a gap of at least 6 months between their approach to patients and our. We have compared lists of patients and prioritized our subject invitation plan and scheduling of interviews in accordance with this agreement.

Patient enrollment is now ready to begin. Letters, opt-out cards, and consent forms are ready to be sent and patient interviews to begin. While the development phase of this project took rather longer than expected, we are hopeful that accrual of subjects will occur quickly and that the interviews will be completed on the original schedule.

Key Research Accomplishments

- Development of interview schedule and demographic and family history form.
- Piloting of PM version of interview
- Surgeons willing to involve patients, encouraging of value of research
- Pilot PM subjects very willing to participate, suggesting quick subject accrual
- Uniformity of interview style established
- Themes from pilot interviews suggest potential areas of interest in analysis of research interviews.

Reportable Outcomes

The PI, Dr. Patenaude, presented a talk at the annual meeting of the American Psychological Association in Washington DC in August 2000 entitled, "DNA, Damocles, and Decision-Making" based on this work in progress.

Conclusions

1. Women with history of PM appear eager to discuss their experience.
2. Surgeons were highly cooperative in providing patient information and permission to contact their patients for this project and were supportive of the value of the project.
3. Demographic and family history forms developed for this project appear easily administered.
4. Research interview transcripts should be reviewed for expectations of coercion by psychologists providing pre-surgical consultation.
5. Analysis of research interview transcripts should pay careful attention to subject report of body image and attractiveness negative self-perceptions.

"So What?" Section:

The number of women making decisions about prophylactic mastectomy is increasing rapidly as more women undergo genetic testing and are identified at increased genetic risk for breast cancer. Researchers recognize that emotional factors play a major role in decision-making about PM. Understanding what women experience as sequelae of

PM and what women considering PM want to know will improve the likely utility of a psychological consultation offered to women prior to surgery. Understanding barriers to the utilization of such a consultation intervention (such as the perception that psychologists coerce patients to make a particular decision regarding PM) can inform the development of the intervention in ways which overcome these barriers. It is important that the research guiding the development of a PM intervention reflect the views of a representative sample of women who have undergone PM (historically a relatively small group). Hence, the high level of surgeon co-operation and the eager participation of pilot PM subjects encourages us that this project will yield information based on a representative sample of women who had prophylactic mastectomies in the past decade. Having user-friendly, easily-completed forms will similarly lower risk of missing data or discouragement of participation by subjects. Our careful work to date, high participation rate by surgeons and ease of attracting pilot subjects suggest that we will be able to collect data which will prove appropriate and valuable in the development of a potentially very useful intervention for women considering PM.

Appendices:

1. Interview Schedule for PM patients
2. Demographic and family history form for all patients
3. Brochure from Dr. Patenaude's talk at the American Psychological Association meeting in Washington DC, August 2000

INTERVIEW OUTLINE
FOR WOMEN WHO HAVE HAD A PROPHYLACTIC MASTECTOMY.

ID Code #_____

Date:_____

Time Started:_____
Time Finished:_____
Total Time:_____

DECISION-MAKING **Global Question 1: Could you please describe for me how you made your decision to have a prophylactic mastectomy (PM)? When did you first learn about PM, how did you think about it, who did you talk to, and how did you come to your final plan?**

Probes (Ask only if not mentioned in narrative):

1a. What do you think you were hoping would be better about your life by undergoing this procedure? What were your personal aims or goals? How has it turned out?

1b. How much were you worrying about cancer before surgery and how different, if at all, is your worry about cancer now?

1c. Pre-surgery were you the kind of person who had mammograms and other screening tests right on time, put them off a little, or tended to avoid them?

1d. Were there some aspects of your own experience with cancer in your family which you were trying to avoid re-experiencing?

1e. Who, if anybody, had the most influence on your decision about PM? How did they influence you?

1f. Did your doctors make any recommendations about PM or not? How do you feel about the communication you had with your doctors about PM?

1g. When you were making your decision, what did you most want to know? Was any part of the information you got confusing? Did you have the information you wanted?

1h. As you were making your decision, did you talk to anyone who had had a PM? was that helpful?

1i. Was it clear to you as you were making your decision that there was some residual risk of breast cancer even after having a PM? YES?NO

(If NO): Would knowing that have made a difference in your decision, do you think?

(For All): How do you cope with knowing that?

1j. Was your partner (if had one then) consulted? If yes, how was he/she involved? Did you find their involvement helpful or not? What was their reaction to your decision?

1k. Do you think you are good at making medical decisions? Would you change anything about the way you approached this decision with the hindsight you now have?

SURGICAL EXPERIENCE **Global Question 2: Could you please tell me what it was like to undergo your prophylactic mastectomy surgery? How did you feel going into the surgery and how did you find the recovery period?**

Probes (Ask only if not mentioned in the narrative):

2a. Why did you choose to have the surgery at the time you did?

2b. Did you have any hesitation about scheduling the surgery or keeping the appointment for surgery?

2c. In the time leading up to the surgery, would you say that you had felt support or opposition or neither from the people closest to you? Were there any people close to you whom you didn't tell about your impending surgery?

2d. What was it like for you right after surgery? Was it different than you expected ?

2e. How did you feel about your body the first time the bandages were removed? What was helpful and what was not in adjusting to the way your body now looked?

2f. Did you have any particular problems with pain management after surgery? Any complications?

2g. What was the mobility of your arms like in the weeks and months following surgery?

2h. (For cancer patients): Did your treatment complicate your recovery from surgery in any way?

2i. What went into your decision about having not having reconstruction? How did you decide about reconstruction?

If had reconstruction: How did you decide when to have the reconstruction?
Any problems with the reconstruction?

SURGICAL SEQUELAE/RECOVERY **Global Question #3: What was it like for you after surgery? Was there an evolution in your feelings about your prophylactic mastectomy or did you feel pretty much the same about it from the time of surgery onward? If your feelings evolved, what were the turning points that resulted in your feeling differently about your surgery?**

Probes: (Ask only if not discussed in the narrative):

3a. (If had reconstruction) What was it like emotionally to adjust to having a new breast?

3b. How do you currently feel about your body?

3c. (For cancer patients):Has there been any difference in your feelings about the breast removed for cancer and the breast removed prophylactically?

3d. Has your ability to play sports been affected at all?

3e. Do you ever feel uncomfortable in dressing room or locker room situations because of your breasts?

3f. How have your mastectomies affected your sense of your own sexual attractiveness? Your interest in or enjoyment of sex?

FAMILY INVOLVEMENT- **Global Question #4-Spouse/Partner (For subjects with a spouse or partner): How did your partner react to your having had prophylactic surgery? Was there any change in your sexual relationship which you would attribute to your mastectomies?**
Did you see any change in your overall relationship, for better or worse?

Global Question #5-Children (For subjects with children): What did you tell your children at the time about your surgery and how have you talked about it with them since then, if at all?

Probes (Ask only if not discussed in narrative response):

5a. What have your children asked about your prophylactic surgery? How have you responded?

5b. How important was having children to your decision to have prophylactic surgery?

5c. Have you made suggestions to other family members about them having prophylactic mastectomies?

MENTAL HEALTH INVOLVMENT Global Question #6 How useful was it/would it have been to have a psychological consultation built into the pre-surgical consultation for PM?

Probes:

6a. If you had services during the pre-surgical period, were they helpful? In what way?

6b. If you didn't have mental health services during this period, did you consider talking to someone and if so, what prevented you from doing so?

How do you think the counselor would have counseled/advised you?

6c. Have you found mental health services useful at other times in your life?

6d. How do you think you would have reacted if the surgeon you saw for your pre-surgical consultation had told you that speaking with a psychologist or other counselor had been a standard part of the pre-surgical work-up?

6e. Would it have been helpful to be able to talk with a therapist after your surgery?

6f. Do you think it would have been helpful if

a.) the pre-surgical session had included role-playing or rehearsal of your feelings following surgery.

b.)

or if any of the sessions had included

c.) relaxation training or

d.) a couples session with you and your partner?

6g. Would cost have been a barrier to seeing a counselor about PM?

6h. Any suggestions about the ideal nature or timing or frequency of counselor involvement for people undergoing PM?

SATISFACTION Global Question #7 Overall, how satisfied are you with your prophylactic mastectomy? With your reconstruction (if applicable), with the emotional support you got from family, friends, professionals?

Probes: (Ask only if not covered in narrative)

7a. How do you think it would be different for you today if you hadn't chosen to have a prophylactic surgery?

7b. Did life come back to a place that you would call normal after your PM? If so, when would you say that occurred?

7c. Any regrets?

7d. Any suggestions for women considering PM?

Time ended:_____

Interviewer Comments/Themes

ID CODE:_____

PROPHYLACTIC MASTECTOMY STUDY
DEMOGRAPHIC FORM

We would appreciate it if you would please answer all of the following questions as they apply to you. If none of the answers provided seems exactly right, please choose the answer that comes nearest to being right for you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential and will not be linked to you by name. If you do not want to answer a particular question, please write "Chose Not To Answer" (so we know it is not an omission) and go on to the next question.

PERSONAL INFORMATION

1.

Today's Date:_____

YOUR STREET ADDRESS:

CITY: STATE: ZIP:

2. HOME PHONE NUMBER:

AREA CODE: TELEPHONE NUMBER:

Okay to call you at this number (Please circle one)? Yes No

3. WORK PHONE NUMBER:

AREA CODE: TELEPHONE NUMBER:

Okay to call you at this number (Please circle one)? Yes No

4. THE BEST TIME AND PLACE TO REACH ME IS AT (PLEASE CHECK OFF YOUR PREFERENCE):

_____HOME PHONE TIME (S):_____

_____WORK PHONE TIME (S):_____

5. WHAT IS YOUR AGE TODAY (i.e., 44, 56, etc)?
6. WHAT IS YOUR BIRTHDATE (i.e. 3/11/58)?

MARITAL STATUS			
	7. PLEASE CHECK YOUR MARITAL STATUS AT THE **PRESENT MOMENT**		8. PLEASE CHECK YOUR MARITAL STATUS AT THE TIME OF YOUR **PROPHYLACTIC MASTECTOMY**?
	SINGLE		SINGLE
	MARRIED		MARRIED
	LIVING WITH OTHER		LIVING WITH OTHER
	SEPARATED/DIVORCED		SEPARATED/DIVORCED
	WIDOWED		WIDOWED
	OTHER (PLEASE SPECIFY)		OTHER (PLEASE SPECIFY)

9. DO YOU HAVE CHILDREN? (PLEASE CIRCLE ONE)	YES	NO
If YES, please tell:	SONS:	DAUGHTERS:
	HOW MANY SONS?	HOW MANY DAUGHTERS?
	SONS' AGES TODAY?	DAUGHTERS' AGES TODAY?
	SONS' AGES AT TIME OF PROPHYLACTIC MASTECTOMY?	DAUGHTERS' AGES AT TIME OF PROPHYLACTIC MASTECTOMY?

PLEASE CHECK BOX WHICH APPLIES:		
HIGHEST EDUCATIONAL GRADE ACHIEVED	10. YOU COMPLETED	11. IF LIVING IN SAME HOUSEHOLD: YOUR SPOUSE PARTNER COMPLETED
LESS THAN SEVENTH GRADE		
JUNIOR HIGH SCHOOL (9TH GRADE)		
PARTIAL HIGH SCHOOL (10 OR 11TH GRADE)		
HIGH SCHOOL GRADUATE		
PARTIAL COLLEGE (AT LEAST ONE YEAR) OR SPECIALIZED TRAINING		
STANDARD COLLEGE OR UNIVERSITY GRADUATION		
GRADUATE PROFESSIONAL TRAINING (GRADUATE DEGREE)		

12. PLEASE PLACE A CHECK IN THE BOX NEXT TO YOUR TOTAL FAMILY INCOME			
Less than $15.000		$50.000-$74.999	
$15.000- $29.999		$75.000-$99.999	
$30.000-49.999		$100.000 or above	

OCCUPATION	
13. WHAT IS YOUR USUAL (OR LAST) OCCUPATION?	
14. IF LIVING IN SAME HOUSEHOLD, SPOUSE/PARTNER'S OCCUPATION?	

15. PLEASE PLACE A CHECK NEXT TO WHAT BEST DESCRIBES YOUR CURRENT WORK STATUS:			
EMPLOYED: FULL-TIME		HOMEMAKER	
PART-TIME		DISABLED	
NOT EMPLOYED		LAID OFF	
ON SICK LEAVE		UNEMPLOYED, BUT LOOKING FOR WORK	
RETIRED		OTHER:	

16. WHAT RACE/ETHNICITY DO YOU CONSIDER YOURSELF TO BE?			
AFRICAN-AMERICAN		CAUCASIAN	
ASIAN/PACIFIC		HISPANIC	
NATIVE-AMERICAN		OTHER:	

17. DO YOU HAVE A RELIGIOUS PREFERENCE?			
CATHOLIC		PROTESTANT	
JEWISH		NONE	
ISLAMIC		OTHER:	

SURGICAL HISTORY

RIGHT BREAST		
	PROPHYLACTIC (PREVENTATIVE)?	FOR TREATMENT OF CANCER IN THAT BREAST?
18. WAS THE MASTECTOMY ON YOUR RIGHT BREAST (PLEASE CHECK ONE):		

PLEASE PROVIDE THE DATE OF THE MASTECTOMY ON YOUR RIGHT BREAST: MONTH:_____ YEAR:_____	
PLEASE PROVIDE YOUR SURGEON'S NAME:	AND HOSPITAL:

LEFT BREAST

	PROPHYLACTIC (PREVENTATIVE)?	FOR TREATMENT OF CANCER IN THAT BREAST?
19. WAS THE MASTECTOMY ON YOUR LEFT BREAST (PLEASE CHECK ONE):		

PLEASE PROVIDE THE DATE OF THE MASTECTOMY ON YOUR LEFT BREAST: MONTH:_____ YEAR:_____	
PLEASE PROVIDE YOUR SURGEON'S NAME:	AND HOSPITAL:

20. DID YOU HAVE RECONSTRUCTIVE SURGERY AT THE TIME OF YOUR MASTECTOMIES (PLEASE CIRCLE ONE)? (INCLUDING BREAST IMPLANT OR FLAP PROCEDURE)	YES	NO
IF NO, DID YOU HAVE RECONSTRUCTIVE SURGERY AT A LATER TIME? (PLEASE CIRCLE ONE)	YES	NO

21. HAVE YOU HAD YOUR OVARIES REMOVED? (PLEASE CIRCLE ONE)	YES	NO

IF **YES**.

MONTH:_____ YEAR:_____

REASONS OVARIES REMOVED:
(PLEASE CHECK ONE)

	BECAUSE OF CANCER		PROPHYLACTICALLY (PREVENTATIVELY)
	OTHER (PLEASE EXPLAIN):		

MEDICAL HISTORY

22. HAVE YOU EVER BEEN DIAGNOSED WITH DUCTAL CARCINOMA IN SITU (DCIS) (PLEASE CIRCLE ONE)? (IF NO, PLEASE SKIP TO THE NEXT QUESTION)	YES	NO
DCIS WAS IN (PLEASE CIRCLE ONE):	RIGHT BREAST?	LEFT BREAST?

IF YES: DATE(S) OF DIAGNOSIS?

MONTH:_____ YEAR:_____

MONTH:_____ YEAR:_____

HOW OLD WERE YOU? _____

23. HAVE YOU EVER BEEN DIAGNOSED WITH BREAST CANCER (PLEASE CIRCLE ONE)? (IF NO, PLEASE SKIP TO THE NEXT QUESTION)	YES	NO
CANCER WAS IN (PLEASE CIRCLE ONE):	RIGHT BREAST	LEFT BREAST
IF YES: DATE(S) OF DIAGNOSIS? MONTH:_____ YEAR:_____ MONTH:_____ YEAR:_____		
HOW OLD WERE YOU? _____		

24. HAVE YOU EVER BEEN DIAGNOSED WITH OVARIAN CANCER (PLEASE CIRCLE ONE)? (IF NO, PLEASE SKIP TO THE NEXT QUESTION)	YES	NO
IF YES: DATE(S) OF DIAGNOSIS? MONTH:_____ YEAR:_____ MONTH:_____ YEAR:_____		
HOW OLD WERE YOU? _____		

25. HAVE YOU EVER HAD ANY OTHER CANCER DIAGNOSIS (PLEASE CIRCLE ONE)? (IF NO, PLEASE SKIP TO THE NEXT QUESTION)	YES	NO

IF YES:

THE TYPE OF CANCER:

_____

DATE(S) OF DIAGNOSIS:

MONTH:_____ YEAR:_____

MONTH:_____ YEAR:_____

HOW OLD WERE YOU? _____

26. PLEASE CIRCLE YOUR CURRENT CANCER STATUS?	
NEVER HAD CANCER	HAD CANCER NOT CURRENTLY IN TREATMENT
HAD CANCER CURRENTLY IN TREATMENT	OTHER:

27. IN GENERAL, WOULD YOU SAY YOUR HEALTH IS (PLEASE CIRCLE ONE):				
EXCELLENT	VERY GOOD	GOOD	FAIR	POOR

FAMILY HISTORY

These questions ask about the health of your family members, both living and deceased. Please give information about blood relatives only.

28. PLEASE INDICATE WHICH OF THE FOLLOWING RELATIVES HAVE HAD CANCER?

Breast Cancer BEFORE age 51	Breast Cancer (AFTER age 51	Endometrial Cancer Body of Uterus Womb	Cervix Cancer	Ovary Cancer	Lung Cancer	Leukemia		Hodgkin's Disease or Lymphoma	Colon/Rectum Cancer	Prostate Cancer	Thyroid Cancer	Malignant Melanoma	Other Skin Cancer	None
O	O	O	O	O	O	O	Mother	O	O	O	O	O	O	O
O	O	O	O	O	O	O	Father	O	O	O	O	O	O	O
O	O	O	O	O	O	O	Mother's mother	O	O	O	O	O	O	O
O	O	O	O	O	O	O	Mother's Father	O	O	O	O	O	O	O
O	O	O	O	O	O	O	Father's Mother	O	O	O	O	O	O	O
O	O	O	O	O	O	O	Father's Father	O	O	O	O	O	O	O
O	O	O	O	O	O	O	Sister 1	O	O	O	O	O	O	O
O	O	O	O	O	O	O	Sister 2	O	O	O	O	O	O	O
O	O	O	O	O	O	O	Sister 3	O	O	O	O	O	O	O
O	O	O	O	O	O	O	All other sisters	O	O	O	O	O	O	O
O	O	O	O	O	O	O	Brother 1	O	O	O	O	O	O	O
O	O	O	O	O	O	O	Brother 2	O	O	O	O	O	O	O
O	O	O	O	O	O	O	Brother 3	O	O	O	O	O	O	O
O	O	O	O	O	O	O	All other brothers	O	O	O	O	O	O	O
O	O	O	O	O	O	O	Daughter 1	O	O	O	O	O	O	O
O	O	O	O	O	O	O	Daughter 2	O	O	O	O	O	O	O
O	O	O	O	O	O	O	Daughter 3	O	O	O	O	O	O	O
O	O	O	O	O	O	O	All other daughters	O	O	O	O	O	O	O
O	O	O	O	O	O	O	Son 1	O	O	O	O	O	O	O
O	O	O	O	O	O	O	Son 2	O	O	O	O	O	O	O
O	O	O	O	O	O	O	Son 3	O	O	O	O	O	O	O
O	O	O	O	O	O	O	All other sons	O	O	O	O	O	O	O
O	O	O	O	O	O	O	All Mother's sisters	O	O	O	O	O	O	O
O	O	O	O	O	O	O	All Mother's brothers	O	O	O	O	O	O	O
O	O	O	O	O	O	O	All Father's sisters	O	O	O	O	O	O	O
O	O	O	O	O	O	O	All Father's Brothers	O	O	O	O	O	O	O
O	O	O	O	O	O	O	All Maternal Cousins	O	O	O	O	O	O	O
O	O	O	O	O	O	O	All Paternal Cousins	O	O	O	O	O	O	O

29. HAVE ANY OF YOUR RELATIVES WITH CANCER DIED OF THEIR CANCER?
(PLEASE CHECK YES OR NO)

NO - PLEASE SKIP TO NEXT QUESTION

YES - PLEASE COMPLETE TABLE BELOW

RELATIONSHIP TO YOU (I.E., MOTHER, AUNT, FATHER)	RELATIVE'S AGE AT DEATH	YOUR AGE WHEN THIS RELATIVE DIED

IF YOU NEED MORE SPACE, PLEASE USE THE BACK OF THIS SHEET.

30. DO ANY BLOOD RELATIVES IN YOUR FAMILY HAVE A KNOWN MUTATION IN THEIR BRCA1/2 GENES?
(PLEASE CHECK ONE)

	NO		DON'T WANT TO SAY
	YES - (PLEASE COMPLETE THE TABLE BELOW)		DON'T KNOW

IF YES.

PLEASE INDICATE WHICH BLOOD RELATIVES IN YOUR FAMILY HAVE A KNOWN MUTATION IN THEIR BRCA1/2 GENES BY CHECKING ONE OR MORE BOXES BELOW.

SIDE OF THE FAMILY (PLEASE CHECK ONE)		RELATIONSHIP (SISTER, ETC)
MOTHER	FATHER	
		MOTHER, SISTER, DAUGHTER, FATHER, BROTHER, SON
		MOTHER, SISTER, DAUGHTER, FATHER, BROTHER, SON
		AUNT, UNCLE, GRANDMOTHER, GRANDFATHER
		AUNT, UNCLE, GRANDMOTHER, GRANDFATHER
		COUSIN, NIECE, NEPHEW
		COUSIN, NIECE, NEPHEW

INSURANCE HISTORY

	YES	NO
31. DO YOU HAVE HEALTH INSURANCE?		
32. DO YOU HAVE DISABILITY INSURANCE?		
33. DO YOU HAVE LIFE INSURANCE?		
34. DID YOU SUBMIT PAYMENT FOR YOUR PROPHYLACTIC MASTECTOMY TO YOUR INSURANCE COMPANY?		
IF YES: DID YOUR HEALTH INSURANCE COVER AT LEAST, IN PART YOUR PROPHYLACTIC MASTECTOMY?		
35. *ANSWER ONLY IF YOU HAVE A FAMILY HISTORY OF CANCER HAVE YOU EVER HAD TROUBLE GETTING INSURANCE BECAUSE OF A FAMILY HISTORY OF CANCER?	YES	NO

THIS IS THE END OF THE QUESTIONNAIRE. PLEASE PUT COMPLETED QUESTIONNAIRE IN THE ENCLOSED SELF-ADDRESSED STAMPED ENVELOPE AND MAIL TO THE ADDRESS BELOW AT YOUR EARLIEST CONVENIENCE.

Mail to:
Andrea Patenaude, Ph.D., Dana 363
Dana-Farber Cancer Institute
44 Binney St.
Boston, MA 02115

We will be in touch with you within the next 2 weeks by telephone to schedule an interview time. If you have any questions, please call us:

Dr. Sara Orozco (617) 632-2504

Dr. Andrea Patenaude (617) 632-3314

THANK YOU VERY MUCH.

THE AMERICAN PSYCHOLOGICAL FOUNDATION

and

APA Division 29
Division of Psychotherapy

APA Division 42
Psychologists in Independent Practice

Present the

Seventh Annual
Rosalee G. Weiss Lecture

"DNA, Damocles, and Decision Making"

Delivered by

Andrea Farkas Patenaude, Ph.D.

Presenters:

Joseph D. Matarazzo, Ph.D., APF President
John C. Norcross, Ph.D., Division 29 President
Elaine Rodino, Ph.D., Division 42 President

Sunday, August 6, 2000
1:00 to 1:50 p.m.
Grand Hyatt Washington Hotel
Lafayette Park Room

About Rosalee G. Weiss, Ph.D.

Rosalee Greenfield Weiss, Ph.D., has led a life of varied careers. As a child, Dr. Weiss became a professionally trained ballet artist, making her first stage appearance at age [illegible]. As a young woman, she pursued acting and modeling careers and she was invited to become a member of the Russian Ballet. Then, reluctantly heeding her father's advice, she became a pre-medical student at Mather College, at Case Western Reserve University.

There, Weiss began her interest in psychology through her association with professor and chair of the psychology department, Dr. Calvin S. Hall. She received her baccalaureate from Case Western in 1949.

Raymond A. Weiss

Weiss earned her master's and doctoral degrees in psychology from New York University (NYU). She became Senior Clinical Research Psychologist for the State of New Jersey at the Diagnostic Center in Menlo Park. Here, she supervised other clinical psychologists, researched problems of crime and delinquency with an emphasis on sex offenders, and conducted clinical assessment and therapy with victims and individuals convicted of such crimes.

After leaving the Diagnostic Center, Weiss continued her clinical practice in Teaneck, New Jersey, while serving as a consultant to school systems, institutions, and agencies. In the early 1980s, Weiss and her husband, Raymond A. Weiss, Ph.D., formed Weiss and Weiss, Psychological Associates, P.A., where they currently practice as licensed psychologists.

About Raymond A. Weiss and the Rosalee G. Weiss Lecture Series

Raymond A. Weiss, Ph.D., Ed.D., received his doctoral degrees from New York University (NYU) and Columbia University. After serving in WWII, he taught, conducted research, and held administrative positions at NYU. In 1981, Dr. Weiss took an "early retirement" from the university and completed the requirements to become a licensed psychologist. In 1984, he joined his wife, Rosalee, to form Weiss & Weiss Psychological Associates, P.A.

Weiss established the Rosalee G. Weiss Lecture Series in 1994 [illegible] his wife. Annual gifts support the series, and a bequest will perpetuate it. Divisions 29 and 42 are responsible for the APF Board of Trustees select an annual distinguished speaker at the APA convention. The individual must be an outstanding leader in the arts and sciences whose career is not directly in the spheres encompassed by psychology or an outstanding leader in any of the specialty areas within the sphere of psychology.

About Andrea Farkas Patenaude, Ph.D.

Andrea Farkas Patenaude is a clinical psychologist and researcher. She is director of psycho-oncology research in the division of pediatric oncology at the Dana-Farber Cancer Institute, in Boston, and she is assistant professor of psychology in the department of psychiatry at the Harvard Medical School. Her current research focuses on psychological outcomes of cancer genetic testing. She has studied long-term emotional outcomes for survivors of pediatric cancer and is interested in the transition of chronically ill pediatric patients to adult services.

She has also studied informed consent and other aspects of doctor–patient communication, and she teaches medical students about communicating with seriously ill patients. She has previously worked clinically with pediatric cancer and bone marrow transplant patients, and she has been strongly involved in the education of psychology interns and post-doctoral fellows. For the past thirty years, she has also worked with child, adolescent, and adult patients in a small private practice.

Dr. Patenaude has authored or co-authored numerous articles on the research areas noted above in the major medical and psychological journals. She is a Fellow of the APA Division of Health Psychology and has served for several years as the co-chair of the APA Advisory Council on Genetic Issues.

American Psychological Foundation

The American Psychological Foundation is a 501 c 3 organization established in 1953 to promote psychology and to help extend its benefits to the public. Today APF continues to contribute to both the practice and the science of psychology to the understanding of behavior and the benefit of human welfare.

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For more information on the Foundation or on the Rosalee G. Weiss Lecture Fund, please call 202-336-5843, or Email: foundation@apa.org

APA Division of Psychotherapy

The Division of Psychotherapy (Division 29) is a professional and scientific organization that seeks to promote education, research, high standards of practice, and exchange of information among psychologists interested in psychotherapy.

For more information on Division 29, please contact the Division 29 Central Office, Tracey Martin, 6557 East Riverdale Street, Mesa, AZ 85215; Telephone: (602) 363-9211; Email: assnmgmt@aol.com

APA Division of Psychologists in Independent Practice

The Division of Psychologists in Independent Practice (Division 42) deals with issues affecting psychological services in all independent practice settings and advocates on behalf of consumers of these services. Through its committees and task forces, it works toward promoting quality and accessibility.

For more information on Division 42, please contact the Division 42 Central Office, Jeannie Beeaff, 919 West Marshall Avenue, Phoenix, AZ 85013; Telephone: (602) 246-6768; Email: div42apa@primenet.com