PARENT/GUARDIAN STUDY ID	
DAUGHTER STUDY ID	
DAUGHTER'S AGE	
TODAY'S DATE	MONTH DAY YEAR

The LEGACY Girls Study

Baseline Parent/Guardian Questionnaire

For parents/guardians with daughters age 6-11 years

Behavioral Questions

Self-administered

- A. Your daughter's feelings and behaviors
- B. Your feelings in the past week
- C. Your feelings and thoughts in the past month
- D. Your health behaviors
- E. Cancer screening and surgery
- F. Your thoughts and opinions about breast cancer
- G. Your family

This survey is going to cover several topics. The first set of questions may seem a little different than what you expected. They are not about health or breast cancer. They are questions often used in research to understand how children may act. Next are questions about how you think or feel, your health behaviors, and your opinions and experiences with breast cancer and your family relationships. You may skip any question you would rather not answer.

SECTION A. YOUR DAUGHTER'S FEELINGS AND BEHAVIORS

Directions: On the pages that follow are phrases that describe how children may act. Please read each phrase and mark the response that describes how your daughter has behaved recently (in the last several months).

Select **Never** if the behavior **never** occurs.

Select **Sometimes** if the behavior **sometimes** occurs.

Select Often if the behavior often occurs.

Select Almost Always if the behavior almost always occurs.

Please mark every item. If you don't know or are unsure of your response to an item, give your best estimate.

		Never	Some- times	Often	Almost always
A1.	Worries.				
A2.	Cannot wait to take turn.				
A3.	Teases others.				
A4.	Is easily upset.				
A5.	Worries about what teachers think.				
A6.	Is too serious.				
A7.	Disobeys.				
A8.	Complains about being teased.				
A9.	Is unable to slow down.				
A10.	Bullies others.				
A11.	Hits other children.				
A12.	Cries easily.				
A13.	Steals.				
A14.	Expresses fear of getting sick.				
A15.	Worries about making mistakes.				

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		Never	Some- times	Often	Almost always
A16.	Worries about what parents think.				
A17.	Disrupts other children's activities.				
A18.	Argues with parents.				
A19.	Says, "Nobody understands me."				
A20.	Worries about schoolwork.				
A21.	Is fearful.				
A22.	Breaks the rules.				
A23.	Complains about not having friends.				
A24.	Acts out of control.				
A25.	Complains of pain.				
A26.	Argues when denied own way.				
A27.	Threatens to hurt others.				
A28.	Has stomach problems.				
A29.	Says, "Nobody likes me."				
A30.	Lies to get out of trouble.				
A31.	Says, "I think I'm sick."				
A32.	Tries too hard to please others.				
A33.	Is nervous.				
A34.	Fiddles with things while at meals.				
A35.	Annoys others on purpose.				
A36.	Is negative about things.				
A37.	Worries about things that cannot be changed	l. 🗌			
A38.	Deceives others.				
A39.	Says, "I don't have any friends."				
A40.	Is overly active.				
A41.	Has headaches.				
A42.	Seeks revenge on others.				
A43.	Loses temper too easily.				
A44.	Complains about health				

		Never	Some- times	Often	Almost always
A45.	Says, "I want to die" or "I wish I were dead."				
A46.	Sneaks around.				
A47.	Gets sick.				
A48.	Says, "I'm afraid I will make a mistake."				
A49.	Interrupts others when they are speaking.				
A50.	Calls other children names.				
A51.	Says, "I hate myself."				
A52.	Says, "I'm not very good at this."				
A53.	Lies.				
A54.	Is sad.				
A55.	Acts without thinking.				
A56.	Has fevers.				
A57.	Is afraid of getting sick.				
A58.	Seems lonely.				
A59.	Breaks the rules just to see what will happen.				
A60.	Complains of being sick when				
	nothing is wrong.				
A61.	Says, "It's all my fault."				
A62.	Interrupts parents when they are talking				
	on the phone.				
A63.	Is cruel to others.				
A64.	Says, "I want to kill myself."				
A65.	Worries about what other children think.				
A66.	Has poor self control.				
A67.	Vomits.				
A68.	Changes moods quickly.				
A69.	Gets into trouble.				
A70.	Complains of shortness of breath.				

SECTION B. YOUR FEELINGS IN THE PAST WEEK

The next several questions are about how \underline{you} have been feeling. For each item please check the reply that comes closest to how you have been feeling in the past week. Don't take too long to think over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

B1.	I feel tense or 'wound up':
	 ☐ Most of the time ☐ A lot of the time ☐ From time to time, occasionally ☐ Not at all
B2.	I still enjoy the things I used to enjoy:
	☐ Definitely as much ☐ Not quite so much ☐ Only a little ☐ Hardly at all
B3.	I get a sort of frightened feeling as if something awful is about to happen:
	 □ Very definitely and quite badly □ Yes, but not too badly □ A little, but it doesn't worry me □ Not at all
B4.	I can laugh and see the funny side of things:
	 ☐ As much as I always could ☐ Not quite so much now ☐ Definitely not so much now ☐ Not at all
B5.	Worrying thoughts go through my mind:
	☐ A great deal of the time ☐ A lot of the time ☐ Not too often ☐ Very little

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B6.	I feel cheerful:
	NeverNot oftenSometimesMost of the time
B7.	I can sit at ease and feel relaxed:
	☐ Definitely ☐ Usually ☐ Not often ☐ Not at all
B8.	I feel as if I am slowed down:
	Nearly all the timeVery oftenSometimesNot at all
B9.	I get a sort of frightened feeling like 'butterflies' in the stomach:
	Not at allOccasionallyQuite oftenVery often
B10.	I have lost interest in my appearance:
	 □ Definitely □ I don't take as much care as I should □ I may not take quite as much care □ I take just as much care as ever
B11.	I feel restless as if I have to be on the move:
	☐ Very much indeed☐ Quite a lot☐ Not very much☐ Not at all
B12.	I look forward with enjoyment to things:
	As much as ever I did Rather less than I used to Definitely less than I used to Hardly at all
B13.	I get sudden feelings of panic:
	 □ Very often indeed □ Quite often □ Not very often □ Not at all

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B14.	I can enjoy a good book or radio or television program:
	☐ Often ☐ Sometimes ☐ Not often
	☐ Very seldom
	SECTION C. YOUR FEELINGS & THOUGHTS IN THE PAST MONTH
	questions in this section ask you about your feelings and thoughts during the last month. For question, please tell us how often you felt or thought a certain way.
C1.	In the last month, how often have you felt that you were unable to control the important things in your life?
	 Never Almost never Sometimes Fairly often Very often
C2.	In the last month, how often have you felt confident about your ability to handle your personal problems? I am not asking how often you have had personal (work, friends, family) problems, but how often, when you had a problem, you felt confident to handle it.
	 Never Almost never Sometimes Fairly often Very often
C3.	In the last month, how often have you felt that things were going your way?
	 Never Almost never Sometimes Fairly often Very often
C4.	In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?
	 Never Almost never Sometimes Fairly often Very often

SECTION D. YOUR HEALTH BEHAVIORS

Now we are going to switch gears and ask you more specific questions about some of your health behaviors.

D1.	When	you are out in the sun, how often do you wear sunscreen?
	Soi	ver rely metimes st of the time vays
D2.		the past 30 days have you had at least one drink of an alcoholic beverage, such as beer, malt beverage or liquor?
	☐ Yes	S → GO TO QUESTION D3
	D2.a)	During the past 30 days, how many days per week or per month have you had at least one drink of an alcoholic beverage?
		days per week or days in the past 30 days
		don't know, not sure
	D2.b)	During the past 30 days, on the days that you drank, how many drinks did you drink on average? One drink equals one 12 oz beer, one 5 oz wine, or 1 shot of liquor.
		drinks per day
	D2.c)	Considering all types of alcohol, how many times in the past 30 days did you have four or more drinks on one occasion?
		times
	D2.d)	During the past 30 days, what is the largest number of drinks you had on one occasion?
		drinks
		☐ I don't know

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D3.	How would you describe your body weight?
	 □ very underweight □ slightly underweight □ about the right weight □ slightly overweight □ very overweight
D4.	Which of the following are you trying to do now?
	 ☐ lose weight ☐ gain weight ☐ stay the same weight ☐ not trying to do anything about my weight
D5.	During the past 7 days, how many times did you eat fruit? Do not count fruit juice.
	☐ I did not eat fruit during the past 7 days ☐ 1 to 3 times during the past 7 days ☐ 4 to 6 times during the past 7 days ☐ 1 time per day ☐ 2 times per day ☐ 3 times per day ☐ 4 or more times per day
D6.	During the past 7 days, how many times did you eat green salad or other vegetables?
	☐ I did not eat green salad during the past 7 days ☐ 1 to 3 times during the past 7 days ☐ 4 to 6 times during the past 7 days ☐ 1 time per day ☐ 2 times per day ☐ 3 times per day ☐ 4 or more times per day
D7.	During the past 7 days, how many times did you eat sweets (candy, cookies, cake, ice cream, pastry, etc.)?
	☐ I did not eat sweets during the past 7 days ☐ 1 to 3 times during the past 7 days ☐ 4 to 6 times during the past 7 days ☐ 1 time per day ☐ 2 times per day ☐ 3 times per day ☐ 4 or more times per day

D8.	During the past 7 days, how many times did you drink a can, bottle, or glass of soda or pop, such as Coke, Pepsi, or Sprite? Do not include diet soda or diet pop.
	☐ I did not drink soda or pop during the past 7 days ☐ 1 to 3 times during the past 7 days ☐ 4 to 6 times during the past 7 days ☐ 1 time per day ☐ 2 times per day ☐ 3 times per day ☐ 4 or more times per day
D9.	During the past 7 days, how many glasses of milk did you drink? Include the milk you drank in a glass or cup, from a carton, or with cereal.
	☐ I did not drink milk during the past 7 days☐ 1 to 3 glasses during the past 7 days
	4 to 6 glasses during the past 7 days1 glass per day
	☐ 2 glasses per day☐ 3 glasses per day
	4 or more glasses per day
D10.	During the past 7 days, how many times did you eat fried food (French fries, fried chicken, bacon, potato chips, etc.)?
	I did not eat fried foods during the past 7 days
	1 to 3 times during the past 7 days 4 to 6 times during the past 7 days
	☐ 1 time per day☐ 2 times per day
	☐ 3 times per day☐ 4 or more times per day
D11.	During the past 7 days, how many times did you eat red meat (hamburgers, steak, barbecue, beef tacos, etc.)?
	☐ I did not eat red meat during the past 7 days ☐ 1 to 3 times during the past 7 days ☐ 4 to 6 times during the past 7 days ☐ 1 time per day ☐ 2 times per day ☐ 3 times per day
	4 or more times per day

SECTION E. CANCER SCREENING AND SURGERY

The next several questions are about cancer screening and surgery.

E1.	Have you had a bilateral mastectomy (both breasts removed) either for treatment or prevention of breast cancer?
	 No → Continue Yes, treatment related → Go to E6 Yes, prevention → Go to E6
E2.	Have you had a screening mammogram in the last 12 months?
	 Yes → Go to E2.b No→ Go to E2.a I have never had a mammogram → Go to E3
	E2.a) My last screening mammogram was years ago.
	E2.b) I have a screening mammogram every year. Never Rarely Sometimes Often Always
E3.	Do you get breast MRI to screen for breast cancer? A breast MRI is a procedure in which radio waves and a powerful magnet linked to a computer are used to create detailed pictures of areas inside the body.
	Yes → Go to Question E3.aNo → Go to Question E4
	E3.a) My last breast MRI wasmonths ago oryears ago.
E4.	Have you had a breast exam performed by a health care professional in the last 12 months?
	Yes → Go to Question E4.bNo → Go to Question E4.a
	E4.a) My last clinical breast exam wasyears ago.
	E4.b) I have a clinical breast exam every year. Never Rarely Sometimes Often Always

Questionnaire #2: final version 3-30-2012

	Yes → Go to Question E5.bNo → Go to Question E5.a				
	E5.a) My last self-breast exa	m wasmor	nths or y	ears ago.	
	E5.b) I perform monthly self-l	breast exams.			
	☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Always				
E	6. Have you had your ovaries removed?				
	☐ No☐ Yes, to prevent cancer☐ Yes, to treat cancer☐ Yes, for other gynecologic or medical rea	sons			
,	SECTION F. YOUR THOUGHTS & OP	INIONS ABO	OUT BREA	AST CANCI	ER
-1. N Pl	ext are some sentences about thoughts and fee ease check each item indicating how true these ays. If they did not occur during that time, mark	elings you may	have had in	the last seve	n days.
-1. N Pl	ext are some sentences about thoughts and fee ease check each item indicating how true these	elings you may	have had in	the last seve	n days.
-1. N Pl	ext are some sentences about thoughts and fee ease check each item indicating how true these	elings you may e comments we "not at all."	have had in ere for you ir	the last seven	n days. en
F1. N Pl da	ext are some sentences about thoughts and fee ease check each item indicating how true these ays. If they did not occur during that time, mark I thought about breast cancer when I didn't	elings you may e comments we "not at all."	have had in ere for you ir	the last seven	n days. en
F1. N PI da	ext are some sentences about thoughts and fee ease check each item indicating how true these eys. If they did not occur during that time, mark I thought about breast cancer when I didn't mean to. I tried to remove breast cancer from my	elings you may e comments we "not at all."	have had in ere for you ir	the last seven	n days. en
F1. N PI da 	ext are some sentences about thoughts and fee ease check each item indicating how true these eys. If they did not occur during that time, mark I thought about breast cancer when I didn't mean to. I tried to remove breast cancer from my memory. I had waves of strong feelings about breast	elings you may e comments we "not at all."	have had in ere for you ir	the last seven	n days. en
-1. N Pl da 	ext are some sentences about thoughts and fee ease check each item indicating how true these ays. If they did not occur during that time, mark I thought about breast cancer when I didn't mean to. I tried to remove breast cancer from my memory. I had waves of strong feelings about breast cancer.	elings you may e comments we "not at all."	have had in ere for you ir	the last seven	n days. en
=1. N PI da ==1a. ==1b.	ext are some sentences about thoughts and fee ease check each item indicating how true these eys. If they did not occur during that time, mark I thought about breast cancer when I didn't mean to. I tried to remove breast cancer from my memory. I had waves of strong feelings about breast cancer. I stayed away from reminders of breast cancer.	elings you may e comments we "not at all."	have had in ere for you ir	the last seven	n days. en
F1. N Pl da F1a. F1c. F1c.	ext are some sentences about thoughts and fee ease check each item indicating how true these eys. If they did not occur during that time, mark I thought about breast cancer when I didn't mean to. I tried to remove breast cancer from my memory. I had waves of strong feelings about breast cancer. I stayed away from reminders of breast cancer. I tried not to talk about breast cancer. Pictures about breast cancer popped into my	elings you may e comments we "not at all."	have had in ere for you ir	the last seven	n days. en
=1. N Pl da =1a. =1b. =1c. =1f.	ext are some sentences about thoughts and fee ease check each item indicating how true these eys. If they did not occur during that time, mark as I thought about breast cancer when I didn't mean to. I tried to remove breast cancer from my memory. I had waves of strong feelings about breast cancer. I stayed away from reminders of breast cancer. I tried not to talk about breast cancer. Pictures about breast cancer popped into my mind. Other things kept making me think about breast	elings you may e comments we "not at all."	have had in ere for you ir	the last seven	n days. en

	How much do you agree or disagree that	Disagree Strongly	Disagree	Neither Agree Nor Disagree	Agree	Agree Strongly		
F2.	If a woman has a family history of cancer on her father's side of the family, she has an increased chance of developing breast cancer							
F3.	If a woman has a family history of cancer on her mother's side of the family, she has an increased chance of developing breast cancer							
F4.	Even if a woman has a family history of cancer, she may not develop cancer.							
F5. O	F5. Out of 100 women who get breast cancer, how many have inherited breast cancer?							
	ow consider the likelihood for any wom 00 from the general population, do you							
W	F7. Now, we would like you to consider women who have a family history of breast cancer. How many women out of a group of 100 women with a family history of breast cancer will get breast cancer at some point in their lives?							
F8. Ar	re you familiar with the breast cancer g	enes, BRCA	1 and BRC	A2?				
☐ Yes ☐ No→ Go to Question F9								
	F8a. Have you received genetic counseling?							
	☐ Yes ☐ No							
	F8b. Have you had genetic testing for BRCA1 and/or BRCA2?							
	Yes→ ContinueNo → Go to Question F8e							
	F8c. IF YES: Did you receive the test results?							
	☐ Yes ☐ No							

F8d. <i>IF YES:</i> Can you please tell us your results?
☐ Negative (no mutation)☐ Positive (a mutation was found)☐ Refuse
F8e. Has anyone in your family (blood relatives) been told he or she has a BRCA 1 or BRCA 2 mutation?
☐ Yes ☐ No ☐ I don't know
F8f. Has anyone in your daughter's <u>father's</u> family (blood relatives) been told he or she has a BRCA 1 or BRCA 2 mutation?
☐ Yes ☐ No ☐ I don't know
F8g. Now, we would like you to consider women who have a change in a breast cancer gene. How many women out of a group of 100 women with a change in a breast cancer gene will get breast cancer at some point in their lives?
F9. Have you ever had breast cancer?
☐ Yes ☐ No
No individual has the same likelihood of getting cancer as the "average person" in the population. Given that <u>you are a unique person</u> , this section asks you what you believe your likelihood of getting breast cancer or getting breast cancer again.
F10. What do you think the chances are that YOU will get breast cancer (again) before age 70? (0-100%)
%.
F11. My chances of getting breast cancer (again) at my age are (0-100%)%
F12. If I were to get breast cancer <i>(again)</i> , I expect it will be at least years before I get breast

	3. Do you think your odds of getting breast cancer (again) are the same or different than those of the average woman? I think my odds are:						
	 Much lower A little lower The same A little higher Much higher 						
Now we are interested in your thoughts and opinions about things that could prevent or delay breast cancer in women. Again, we are not looking for any particular answer, but are interested in what YOU believe. <i>How much do you agree or disagree that</i>							
		Disagree Strongly	Disagree	Neither Agree nor Disagree	Agree	Agree Strongly	l don't know
F14.	I believe that women can do things to prevent or delay getting breast cancer.						
F15.	I believe that women can do things to prevent or delay getting breast cancer EVEN if they have a family history of breast cancer.						
F15a.	Only answer if you are familiar with BRCA1/2; others go to F16: Even if a woman has a change in a breast cancer gene, she can do]	
	things to prevent or delay getting breast cancer.						
F16.	I believe that I can do things to prevent or delay getting breast cancer.						
F17.	If a woman leads a healthy lifestyle, I believe she can prevent or delay getting breast cancer.						
F18.	Even if a woman has a family history of breast cancer, leading a healthy lifestyle will prevent or delay breast cancer.						
F18a.	Only answer if you are familiar with BRCA1/2; others go to F19: Even if a woman has a change in a breast cancer gene, leading a healthy lifestyle will prevent or delay breast cancer.						
F19.	If I lead a healthy lifestyle, I believe I can prevent or delay getting breast cancer.						
F20.	Exercise is effective in preventing or delaying breast cancer for women.						

		Disagree Strongly	Disagree	Neither Agree nor Disagree	Agree	Agree Strongly	I don't know
F21.	Exercise is effective in preventing or delaying breast cancer for women with a family history of breast cancer.						
F21a.	Only answer if you are familiar with BRCA1/2; others go to F22: Exercise is effective in preventing or delaying breast cancer for						
	women with a change in a breast cancer gene.						
F22.	Exercise can help me prevent or delay breast cancer.						
F23.	A healthy diet can help women prevent or delay breast cancer.						
F24.	A healthy diet can help a woman prevent or delay breast cancer, even if she has a family history of breast cancer.						
F24a	Only answer if you are familiar with BRCA1/2; others go to F25: A healthy diet can help a woman prevent or delay breast cancer, even if she has a change in a breast cancer gene.						
F25.	A healthy diet can help me prevent or delay breast cancer.						
F26.	I feel that a woman's relationships with her family might improve if she gets breast cancer.						
F27.	I feel that a woman's relationships with people outside her family might improve if she gets breast cancer.						
F28.	I feel that a woman can maintain her social activities if she gets breast cancer.						
F29.	I feel that a woman can continue working at a job (outside the home) if she gets breast cancer.						
F30.	I feel that a woman can maintain her family responsibilities if she gets breast cancer.						

12

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F31.	I believe breast cancer is curable. Do you					
	☐ Disagree strongly☐ Disagree☐ Neither agree nor disagree☐ Agree☐ Agree strongly					
F32.	I believe science will find a cure for breast ca	ancer in:				
	☐ The next 5 years ☐ 6-25 years ☐ 26-100 years ☐ Over 100 years ☐ Never					
	SECTION G	VOLID I	EAMIL V			
	SECTION G	. TOOK I	-AWIL 1			
This section contains a number of statements about families. Read each statement carefully, and decide how well it describes your own family. You should answer according to how <u>YOU</u> see your family. Try not to spend too much time thinking about each statement, but respond as quickly and as honestly as you can. If you have trouble with a statement, answer with your first reaction.						
	How much do you agree or disagree that	Strongly agree	Agree	Disagree	Strongly disagree	
G1.	Planning family activities is difficult because we misunderstand each other.					
G2.	When someone is upset the others <i>know</i> why.					
G3.	In times of crisis we can turn to each other for support.					
G4.	We cannot talk to each other about the					

sadness we feel.

concerns.

tender feelings.

what they are saying.

instead of hinting at them.

G5.

G6.

G7.

G8.

G9.

G10.

You can't tell how a person is feeling from

Individuals are accepted for what they are.

People come right out and say things

It is difficult to talk to each other about

We can express feelings to each other.

We avoid discussing our fears and

	How much do you agree or disagree that	Strongly agree	Agree	Disagree	Strongly disagree	
G11.	We talk to people directly rather than through go-betweens.					
G12.	There are lots of bad feelings in the family.					
G13.	We often don't say what we mean.					
G14.	We feel accepted for what we are.					
G15.	Making decisions is a problem for our family.					
G16.	We are frank with each other.					
G17.	We are able to make decisions about how to solve problem.					
G18.	We don't get along well together.					
G19.	We don't talk to each other when we are angry.					
G20.	We confide in each other.					
G21.	When we don't like what someone has done, we tell them.					
G22.	 Has your daughter ever received care for a psychological condition (has she seen a therapist, counselor or psychiatrist)? Yes No → Go to "End of Questions" 					
	G22.a <i>If yes,</i> please explain (what type of care/did she take any medication)?					
	G22.b <i>If yes,</i> is she still receiving treatment? Yes No					
	End of Questions					

End of Questions
That is the end of this group of questions. Thank you!