

# **ANESTHESIA AWARENESS REGISTRY**

## *Cover Sheet—Survey 2*

- STEP 1:** Read the two-page Consent Form carefully. Sign and date where it asks for the "Subject's Signature"
- STEP 2:** Complete the one-page Enrollment Form.
- STEP 3:** Complete the Anesthesia Awareness Registry Survey 2.
- STEP 4:** Mail these documents to the Anesthesia Awareness Registry.
- Signed and dated Consent Form
  - Completed Enrollment Form & Anesthesia Awareness Registry Survey

**Notice:** We will send confirmation of receipt of these documents to the mailing address you listed on the Enrollment form. A copy of your signed Consent Form, co-signed by a researcher of the Registry will be mailed to this same address.

**Anesthesia Awareness Registry  
c/o Nora Metzger, M.S.W.  
Anesthesiology, Box 356540, University of Washington, Seattle, WA 98195-6540  
awaredb@uw.edu**

*Please remember that we cannot guarantee the confidentiality of any information sent by e-mail.*

# Enrollment Form

## *Anesthesia Awareness Registry*

Please fill out this contact information so we may send you confirmation of receipt of your documents and send you your copy of the signed consent form. We may use this information to contact you if we need further information concerning your care.

The Anesthesia Awareness Registry will only use this contact information for correspondence that is directly related to the research for this Registry. We will not share or sell this contact information to any other party, company or research organization.

<b>Patient's Address for Correspondence</b>	
<b>Name:</b>	_____
<b>Mailing Address</b>	_____
	_____
	_____
	_____
<b>Phone numbers</b>	
Daytime: (____) _____ - _____	<input type="checkbox"/> Preferred
Evening: (____) _____ - _____	<input type="checkbox"/> Preferred
Cell: (____) _____ - _____	<input type="checkbox"/> Preferred
Best time to call:	_____
<b>E-mail Address</b>	_____
<p><i>Please remember that we cannot guarantee the confidentiality of any information sent by e-mail.</i></p>	



## Consent Form

### Anesthesia Awareness Registry

#### Researchers

Karen B. Domino, MD, MPH	Professor, Anesthesiology	206-616-2669
Christopher D. Kent, MD	Assistant Professor, Anesthesiology	206-616-2669
Karen L. Posner, PhD	Research Professor, Anesthesiology	206-616-2669
Nora Metzger, MSW	Research Coordinator, Anesthesiology	206-616-2669

#### Researcher's Statement

##### INTRODUCTION

You are enrolled in the Anesthesia Awareness Registry. We are asking you to complete a new survey as part of this research study. The purpose of this consent form is to give you the information you will need to help you decide whether to complete this new survey.

You previously completed Survey 1 as part of this research study and consented to maintain a link between your name and survey data until January 1, 2012. A second purpose of this consent form is to notify you that the study will continue beyond January 1, 2012. We are asking your permission to keep the link between your name and all of your survey data until January 1, 2022.

Please read this form carefully. You may ask questions about what we will ask you to do, the risks, the benefits, your rights as a volunteer, or anything else about the research or this form that is not clear. When we have answered all of your questions, you can decide if you want to complete this survey or not, and whether we may keep the link between your name and all of your survey data until January 1, 2022. This process is called "informed consent."

##### PURPOSE OF THE STUDY

We want to learn about factors that may be associated with awareness during general anesthesia. We will use two sets of surveys to find out about any memories patients have of their surgery. We hope that the results of this study will help anesthesiologists care for patients better in the future.

##### STUDY PROCEDURES

If you choose to complete this new written survey, we will ask you to describe the psychological impact of your awareness experience. It includes questions about past traumatic events, such as whether you have experienced sexual assault, physical assault, or other very stressful events. Survey 2 will ask about how you are currently feeling, and includes questions about, for example, feeling as if your future will somehow be cut short. You are free to not answer any question and to stop taking the survey at any time. This survey should take 30-45 minutes to complete.

##### RISKS, STRESS, OR DISCOMFORT

Although we will make every effort to keep your information confidential, no system for protecting your confidentiality can be completely secure. It is still possible that someone could find out you were in this study and could find out information about you. The survey may also bring up unpleasant memories. You may refuse to answer any of the questions in the survey or optional discussion. You can ask questions now and later by contacting Ms. Metzger at 206-616-2669 or any other member of the research team.

We have obtained a Certificate of Confidentiality from the Federal Government. This Certificate is not an endorsement from the Federal Government for our research. Rather, a Certificate of Confidentiality protects your privacy by allowing us to refuse to release your name or other identifying information to anyone outside of the research project and institution, even by a court subpoena, except as described below. In the unlikely event of a federal audit, we may have to reveal your name but only to those authorized representatives. The Certificate of Confidentiality does **not** prevent you or a member of your family from voluntarily releasing information about yourself or your involvement in this research. If an insurer, employer, or other person obtains your written consent to receive research information, then the researchers may not use the Certificate to withhold that information.

##### BENEFITS OF THE STUDY

You will not directly benefit from taking part in this research. We hope that the results of this study will benefit future patients by preventing awareness during general anesthesia and helping patients if it does happen.



# Anesthesia Awareness Registry Survey 2

Today's date \_\_\_\_\_

*In this first section, we would like to collect some general information about you.*

1. In what year were you born? \_\_\_\_\_

2. Gender

- Male  
 Female

3. Race

- Asian/Asian American  
 Pacific Islander/Native Hawaiian  
 Black/African American  
 American Indian/Alaska Native  
 White/Caucasian

Other, specify \_\_\_\_\_

4. Ethnicity

- Hispanic or Latina  
 Non-Hispanic

5. Current marital status

- Single, never married  
 Married, partnered, cohabitating  
 Separated or divorced  
 Widowed

Other, specify \_\_\_\_\_

6. What is the highest level of education you have completed

- High school or less  
 Some college, trade school, certificate, associate degree  
 4-year college  
 Beyond 4-year degree

7. Prior to your awareness experience, did you ever seek treatment by a mental health professional (check all that apply):

Yes →

Individual therapy

Couples or marriage counseling

Group therapy

Other \_\_\_\_\_

No

8. Are you currently seeing a mental health professional (check all that apply):

Yes →

Individual therapy

Couples or marriage counseling

Group therapy

Other \_\_\_\_\_

No

9. Did you take medication for a mental health issue prior to your awareness experience?

Yes

No

10. Are you currently taking any medication for a mental health issue?

Yes

No

**11. Please think back upon your awareness experience and answer the following questions in an honest and sincere way, by selecting a number from 1 to 5.**

**Please answer each question based on your feelings about your awareness experience in the past week. Use the following scale:**

Totally Disagree				Totally Agree	
1	2	3	4	5	

		Totally Disagree				Totally Agree
1.	I feel that this event has become part of my identity.	1	2	3	4	5
2.	This event has become a reference point for the way I understand the world.	1	2	3	4	5
3.	I feel that this event has become a central part of my life story.	1	2	3	4	5
4.	This event has colored the way I think and feel about other experiences.	1	2	3	4	5
5.	This event permanently changed my life.	1	2	3	4	5
6.	I often think about the effects this event will have on my future.	1	2	3	4	5
7.	This event was a turning point in my life.	1	2	3	4	5

**12. Listed below are a number of difficult or stressful things that sometimes happen to people. For each event check one or more of the boxes to the right to indicate that: (a) it happened to you personally (b) you witnessed it happen to someone else (c) you're not sure if it fits, or (d) it doesn't apply to you.**

**Natural disaster (for example, flood, hurricane, tornado, earthquake).**

Happened to me     Witnessed it     Not sure     Doesn't apply

**Fire or explosion.**

Happened to me     Witnessed it     Not sure     Doesn't apply

**Transportation accident (for example, car accident, boat accident, train wreck, plane crash).**

Happened to me     Witnessed it     Not sure     Doesn't apply

**Serious accident at work, home, or during recreational activity.**

Happened to me     Witnessed it     Not sure     Doesn't apply

**Exposure to toxic substance (for example, dangerous chemicals, radiation).**

Happened to me     Witnessed it     Not sure     Doesn't apply

**Physical assault (for example, being attacked, hit, slapped, kicked, beaten up).**

Happened to me     Witnessed it     Not sure     Doesn't apply

**Assault with a weapon (for example, being shot, stabbed, threatened with a knife, gun, bomb).**

Happened to me     Witnessed it     Not sure     Doesn't apply

**Sexual assault (rape, attempted rape, made to perform any type of sexual act through force or threat of harm).**

Happened to me     Witnessed it     Not sure     Doesn't apply

**Other unwanted or uncomfortable sexual experience.**

Happened to me     Witnessed it     Not sure     Doesn't apply

**Combat or exposure to a war-zone (in the military or as a civilian).**

Happened to me     Witnessed it     Not sure     Doesn't apply

**Captivity (for example, being kidnapped, abducted, held hostage, prisoner of war).**

- Happened to me     Witnessed it     Not sure     Doesn't apply

**Life-threatening illness or injury.**

- Happened to me     Witnessed it     Not sure     Doesn't apply

**Severe human suffering.**

- Happened to me     Witnessed it     Not sure     Doesn't apply

**Sudden, violent death (for example, homicide, suicide).**

- Happened to me     Witnessed it     Not sure     Doesn't apply

**Sudden, unexpected death of someone close to you.**

- Happened to me     Witnessed it     Not sure     Doesn't apply

**Serious injury, harm, or death you caused to someone else.**

- Happened to me     Witnessed it     Not sure     Doesn't apply

**Any other very stressful event or experience.**

- Happened to me     Witnessed it     Not sure     Doesn't apply

**13. Below is a list of problems and complaints that people sometimes have in response to awareness under anesthesia. Please read each one carefully, then choose one of the responses to indicate how much you have been bothered by the problem in the last month.**

**Repeated, disturbing memories, thoughts or images of awareness experience.**

- Not at all     A little bit     Moderately     Quite a bit     Extremely

**Repeated, disturbing dreams of the awareness experience.**

- Not at all     A little bit     Moderately     Quite a bit     Extremely

**Suddenly acting or feeling as if the awareness experience was happening again (as if you were reliving it).**

- Not at all     A little bit     Moderately     Quite a bit     Extremely

**Feeling very upset when something reminded you of the awareness experience.**

Not at all  A little bit  Moderately  Quite a bit  Extremely

**Having physical reactions (e.g. heart pounding, trouble breathing, or sweating) when something reminded you of the awareness experience.**

Not at all  A little bit  Moderately  Quite a bit  Extremely

**Avoid thinking about or talking about the awareness experience or avoid having feelings related to it.**

Not at all  A little bit  Moderately  Quite a bit  Extremely

**Avoid activities or situations because they remind you of the awareness experience.**

Not at all  A little bit  Moderately  Quite a bit  Extremely

**Trouble remembering important parts of the awareness experience.**

Not at all  A little bit  Moderately  Quite a bit  Extremely

**Loss of interest in things that you used to enjoy.**

Not at all  A little bit  Moderately  Quite a bit  Extremely

**Feeling distant or cut off from other people.**

Not at all  A little bit  Moderately  Quite a bit  Extremely

**Feeling emotionally numb or being unable to have loving feelings for those close to you.**

Not at all  A little bit  Moderately  Quite a bit  Extremely

**Feeling as if your future will somehow be cut short.**

Not at all  A little bit  Moderately  Quite a bit  Extremely

**Trouble falling or staying asleep.**

Not at all  A little bit  Moderately  Quite a bit  Extremely

**Feeling irritable or having angry outbursts.**

Not at all  A little bit  Moderately  Quite a bit  Extremely

**Having difficulty concentrating.**

Not at all    A little bit    Moderately    Quite a bit    Extremely

**Being "super alert" or watchful or on guard.**

Not at all    A little bit    Moderately    Quite a bit    Extremely

**Feeling jumpy or easily startled.**

Not at all    A little bit    Moderately    Quite a bit    Extremely

Over the last two weeks, how often have you been bothered by any of the following problems

**Little or no interest or pleasure in doing things.**

Not at all    Several days    More than half the days    Nearly every day

**Feeling down, depressed, hopeless.**

Not at all    Several days    More than half the days    Nearly every day

**Trouble falling or staying asleep, or sleeping too much.**

Not at all    Several days    More than half the days    Nearly every day

**Feeling tired or having little energy.**

Not at all    Several days    More than half the days    Nearly every day

**Poor appetite or overeating.**

Not at all    Several days    More than half the days    Nearly every day

**Feeling bad about yourself—or that you are a failure or have let yourself or your family down.**

Not at all    Several days    More than half the days    Nearly every day

**Trouble concentrating on things, such as reading the newspaper or watching television.**

Not at all    Several days    More than half the days    Nearly every day

**Moving or speaking so slowly that other people could have noticed? Or the opposite—being so fidgety and restless that you have been moving around a lot more than usual.**

Not at all    Several days    More than half the days    Nearly every day

**Thoughts that you would be better off dead or of hurting yourself in some way.**

- Not at all    Several days    More than half the days    Nearly every day

**How difficult have these problems made it for you to do your work, take care of things at home, or get along with other people.**

- Not difficult at all    Somewhat difficult    Very difficult    Extremely difficult

**How much are the following statements true for you?**

**There is a special person who is around when you are in need.**

- Strongly agree    Agree    Slightly disagree    Disagree    Strongly disagree

**There is a special person with whom you can share joys and sorrows.**

- Strongly agree    Agree    Slightly disagree    Disagree    Strongly disagree

**Your family really tries to help you.**

- Strongly agree    Agree    Slightly disagree    Disagree    Strongly disagree

**You get the emotional help and support you need from your family.**

- Strongly agree    Agree    Slightly disagree    Disagree    Strongly disagree

**You have a special person who is a real source of comfort to you.**

- Strongly agree    Agree    Slightly disagree    Disagree    Strongly disagree

**Your friends really try to help you.**

- Strongly agree    Agree    Slightly disagree    Disagree    Strongly disagree

**You can count on your friends when things go wrong.**

- Strongly agree    Agree    Slightly disagree    Disagree    Strongly disagree

**You can really talk about your problems with your family.**

- Strongly agree    Agree    Slightly disagree    Disagree    Strongly disagree

**You have friends with whom you can share your joys and sorrows.**

- Strongly agree    Agree    Slightly disagree    Disagree    Strongly disagree

**There is a special person in your life who cares about your feelings.**

Strongly agree  Agree  Slightly disagree  Disagree  Strongly disagree

**Your family is willing to help you make decisions.**

Strongly agree  Agree  Slightly disagree  Disagree  Strongly disagree

**You can talk about your problems with your friends.**

Strongly agree  Agree  Slightly disagree  Disagree  Strongly disagree

**14. The following questions ask how you feel about your quality of life, health, or other areas of your life. Please choose the answer that appears most appropriate. Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last four weeks.**

**How would you rate your quality of life.**

Very poor  Poor  Neither poor nor good  Good  Very good

**How satisfied are you with your health.**

Very poor  Poor  Neither poor nor good  Good  Very good

**The following questions ask about how much you have experienced certain things in the last four weeks.**

**To what extent do you feel that physical pain prevents you from doing what you need to do.**

Not at all  A little  A moderate amount  Very much  An extreme amount

**How much do you need any medical treatment to function in your daily life.**

Not at all  A little  A moderate amount  Very much  An extreme amount

**How much do you enjoy life.**

Not at all  A little  A moderate amount  Very much  An extreme amount

**To what extent do you feel your life to be meaningful.**

Not at all  A little  A moderate amount  Very much  An extreme amount

**How well are you able to concentrate.**

- Not at all    A little    A moderate amount    Very much    Extremely

**How safe do you feel in your daily life.**

- Not at all    A little    A moderate amount    Very much    Extremely

**How healthy is your physical environment.**

- Not at all    A little    A moderate amount    Very much    Extremely

**The following questions ask about how completely you experience or were able to do certain things in the last four weeks.**

**Do you have enough energy for everyday life.**

- Not at all    A little    Moderately    Mostly    Completely

**Are you able to accept your bodily appearance.**

- Not at all    A little    Moderately    Mostly    Completely

**Have you enough money to meet your needs.**

- Not at all    A little    Moderately    Mostly    Completely

**How available to you is the information that you need in your day-to-day life.**

- Not at all    A little    Moderately    Mostly    Completely

**To what extent do you have the opportunity for leisure activities.**

- Not at all    A little    Moderately    Mostly    Completely

**How well are you able to get around.**

- Very poor    Poor    Neither poor nor good    Good    Very good

**How satisfied are you with your sleep.**

Very dissatisfied  Dissatisfied  Neither satisfied nor dissatisfied  Satisfied  Very satisfied

**How satisfied are you with your ability to perform your daily living activities.**

Very dissatisfied  Dissatisfied  Neither satisfied nor dissatisfied  Satisfied  Very satisfied

**How satisfied are you with your capacity for work.**

Very dissatisfied  Dissatisfied  Neither satisfied nor dissatisfied  Satisfied  Very satisfied

**How satisfied are you with yourself.**

Very dissatisfied  Dissatisfied  Neither satisfied nor dissatisfied  Satisfied  Very satisfied

**How satisfied are you with your personal relationships.**

Very dissatisfied  Dissatisfied  Neither satisfied nor dissatisfied  Satisfied  Very satisfied

**How satisfied are you with your sex life.**

Very dissatisfied  Dissatisfied  Neither satisfied nor dissatisfied  Satisfied  Very satisfied

**How satisfied are you with the support you get from your friends?**

Very dissatisfied  Dissatisfied  Neither satisfied nor dissatisfied  Satisfied  Very satisfied

**How satisfied are you with the conditions of your living place.**

Very dissatisfied  Dissatisfied  Neither satisfied nor dissatisfied  Satisfied  Very satisfied

**How satisfied are you with your access to health services.**

Very dissatisfied  Dissatisfied  Neither satisfied nor dissatisfied  Satisfied  Very satisfied

**How satisfied are you with your transport.**

- Very dissatisfied  Dissatisfied  Neither satisfied nor dissatisfied  Satisfied  Very satisfied

**The following question refers to how often you have felt or experienced certain things in the last four weeks.**

**How often do you have negative feelings such as blue mood, despair, anxiety, depression.**

- Never  Seldom  Quite often  Very often  Always

**15. Several common symptoms or bodily sensations are listed below. Please indicate how frequently you experience each symptom**

	Have never or almost never experienced the symptom	Less than 3 or 4 times per year	Every month or so	Every week or so	More than every week
Eyes water					
Itchy eyes or skin					
Ringling in ears					
Temporary deafness					
Lump in throat					
Choking sensations					
Sneezing spells					
Running nose					
Congested nose					
Bleeding nose					
Asthma or wheezing					
Coughing					
Out of breath					
Swollen ankles					
Chest Pains					

	Have never or almost never experienced the symptom	Less than 3 or 4 times per year	Every month or so	Every week or so	More than every week
Racing heart					
Cold hands or feet even in hot weather					
Leg cramps					
Insomnia or difficulty sleeping					
Toothaches					
Upset stomach					
Indigestion					
Heartburn or gas					
Abdominal pain					
Diarrhea					
Constipation					
Hemorrhoids					
Swollen joints					
Stiff or sore muscles					
Back pain					
Sensitive or tender skin					
Face flushes					

	Have never or almost never experienced the symptom	Less than 3 or 4 times per year	Every month or so	Every week or so	More than every week
Tightness in chest					
Skin breaks out in rash					
Acne or pimples on face					
Acne/pimples other than face					
Boils					
Sweat even in cold weather					
Strong reactions to insect bites					
Headaches					
Feeling pressure in head					
Hot flashes					
Chills					
Dizziness					
Feel faint					
Numbness or tingling in any part of body					
Twitching of eyelid					
Twitching other than eyelid					
Hands tremble or shake					

	Have never or almost never experienced the symptom	Less than 3 or 4 times per year	Every month or so	Every week or so	More than every week
Stiff joints					
Sore muscles					
Sore throat					
Sunburn					
Nausea					

*This is the end of our survey. Thank you very much for participating in our study. If you have any questions about this survey or the Anesthesia Awareness Registry, e-mail [awaredb@u.washington.edu](mailto:awaredb@u.washington.edu) (please note we cannot guarantee the confidentiality of e-mail communications) or call the Registry at (206) 616-2669.*