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Long Term Issues Committee Brain Injury – Interdisciplinary Special Interest Group

Study on Aging with Brain Injury

Thank you for your interest and participation in this research survey being conducted by the Long Term Issues Committee of the Brain Injury – Interdisciplinary Special Interest Group of the American Congress of Rehabilitation Medicine. The aim of this study is to gather more information regarding aging with brain injury, especially in the area of health. It is hoped that information gathered through this survey will serve as a resource to survivors of brain injury and their families, rehabilitation professionals, public policy makers and other interested parties.

Individuals completing the survey must meet the following criteria for participation in this research study:

1. Sustained a traumatic brain injury after age 16.
2. Currently at least 10 years post-injury.
3. Currently at least 30 years of age.

The survey requires approximately 30 minutes to complete, and consists of a series of questions addressing background information, lifestyle factors and health issues. You may withdraw from participating and/or choose to refrain from answering whatever question(s) you prefer to omit. All survey forms will be kept entirely confidential, data will be recorded by survey number, and aggregate data will be used solely for research and educational purposes under the supervision of the Long Term Issues Committee.

Results of this survey will be published and presented in professional forums and the BI-ISIG Newsletter, will be forwarded to The Brain Injury Association, and will be available to individuals and organizations by request from the researchers listed on the back side of this page.

Thank you for your assistance and support in this endeavor. Please feel free to contact us should you have any questions or require assistance in survey completion.

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PLEASE MAIL THE COMPLETED SURVEY TO:

**Tina M. Trudel, PhD
Project Coordinator
BI and Aging Study
PO Box 266
Center Ossipee, NH 03814-0266**

BI and AGING STUDY - DEMOGRAPHICS
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1. **Project Identification Number:** _____
2. **Current Date:** _____ / _____ / _____
3. **Date of Injury:** _____ / _____ / _____
4. **Date of Birth:** _____ / _____ / _____
5. **Gender:** Female _____ Male _____
6. **Current Postal / Zip Code:** _____
7. **Race:**

(check one)

WHITE	BLACK	ASIAN / PACIFIC ISLANDER	NATIVE AMERICAN	HISPANIC ORIGIN	OTHER	UNKNOWN

8. **Marital Status:**

(check one row in each column)

	At Time of Injury	Current
Single (a person who has never married)		
Married (a person who is married, whether legally or by common law definition of seven years cohabitation)		
Divorced (a person who is legally divorced)		
Separated (includes both legal separation and living apart from married partner)		
Widowed		
Other		
Unknown		

9. Primary person(s) you live(d) with:

(check one row in each column)

	At Time of Injury	Current
Alone		
Spouse		
Parent(s)		
Sibling(s)		
Child / Children (<21 years of age)		
Other relatives or adult children		
Roommates(s) / Friend(s)		
Significant other (partners, not married)		
Other patients (in hospital or nursing home)		
Other residents (group living situation)		
Personal Care Attendant		
Other		

10. Where were you / are you living:

(check one row in each column)

	At Time of Injury	Current
Private Residence		
Nursing Home		
Community Group Home		
Supported Apartment		
Correctional Institution		
Hotel / Motel		
Homeless		
Hospital (Acute Care)		
Hospital (Rehabilitation)		
Hospital (Other)		
Subacute Care (Hospital Step – Down)		
Post - Acute / Residential Care		
Other		

11. Highest grade of school completed:

(check one)

8th grade or less		9th through 11th grade	
High school diploma or GED		Trade School	
Some college, no degree		Associate's Degree	
Bachelor's degree		Master's Degree	
Doctorate (includes PhD, MD, JD)		Unknown	
Other			

12. What was / is your employment status:

(check one row in each column)

	At Time of Injury	Current
Full-time student (regular class)		
Part-time student (regular class)		
Special Education / other non-regular education		
Competitively employed (paid above minimum wage)		
Homemaker		
Special employed (sheltered, supported)		
Retired		
Unemployed		
Volunteer work		
Other		
Unknown		
If competitively employed, please note average weekly paid hours worked on the line in the appropriate column		

13. Primary Occupation:

(check one row in each column)

	At Time of Injury	Current
Executive, Administrative & Managerial		
Professional Specialty		
Technicians and Related Support		
Sales		
Administrative Support including Clerical		
Private Household Service		
Protective Service		
Service, except Protective and Household		
Farming, Forestry, and Fishing		
Precision Production, Craft, and Repair		
Machine Operators, Assemblers, and Inspectors		
Transportation and Material Moving		
Handlers, Equipment Cleaners, Helpers, and Laborers		
Military Occupations		
Not Applicable		
Unknown		

14. Cause of Injury:

(check one)

Motor Vehicle		Motorcycle	
Bicycle		All Terrain Vehicle	
Other Vehicle		Gunshot Wound	
Assault with Blunt Object		Other Violence (penetrating)	
Water Sports		Field Sports (football, baseball)	
Gymnastics		Winter Sports	
Air Sports		Other Sport (wrestling, rodeo)	
Fall		Hit by falling object	
Pedestrian		Hit by other object	
Unknown		Other	

15. Aside from your brain injury, please describe any other major injuries that occurred related to this episode:

16. Approximately how long were you unconscious (defined as being unaware of your surroundings and unable to respond to your environment)?

(please enter the number of minutes, hours or days that best describe how long you were unconscious; enter 0 if you did not lose consciousness)

Minutes	Hours	Days

17. Approximately how long a period of time did you receive inpatient rehabilitation?

(please use best units of measurement; enter 0 if you did not receive this service)

Days	Weeks	Months	Years

18. Approximately how long a period of time did you receive outpatient rehabilitation?

(please use best units of measurement; enter 0 if you did not receive this service)

Days	Weeks	Months	Years

19. Approximately how long a period of time did you receive residential care or assisted living (group home, supported apartment) services?

(please use best units of measurement; enter 0 if you did not receive this service)

Days	Weeks	Months	Years

20. How often do you currently socialize / visit with friends (not relatives or paid staff)?

Times per month

21. How often do you currently speak with friends over the telephone (not relatives or paid staff)?

Times per month

BI and AGING STUDY – HEALTH FACTORS
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1. Please list any medications you are currently taking on a regular basis, and note how long you have been taking them.

Medication(s)	How long have you been taking this?

2. a) Do you smoke?

YES	NO
-----	----

b) If “yes”:

How many years have you smoked?	How many cigarettes per day?

3. a) Do you drink alcoholic beverages?

YES	NO
-----	----

b) If “yes” -

How many years have you used alcohol?	How many drinks do you have per day?

4. a) Do you use any illegal drugs?

YES	NO
-----	----

b) If “yes” -

Which drug have you used?	In what <u>quantity</u> have you used it?	How <u>often</u> have you used it?	How many years have you used it?

5. a) Have you ever had a seizure?

YES	NO
-----	----

b) If “yes”, are you taking seizure medication?

YES	NO
-----	----

c) And.....if “yes” -

When was your last seizure?	How often do you have seizures?	How long have you taken medication to control seizure activity?

6.

(place answer in each column)

	At time of Injury	Current
Height		

7.

(place answer in each column)

	At time of Injury	Current
Weight		

8. Primary funding of Brain Injury / Rehabilitation Care?

(check one row in each column)

	At Time of Injury	Current
Private Pay		
Medicaid		
Medicaid Waiver		
Medicare		
Vocational Rehabilitation		
Worker’s Compensation		
Auto No Fault		
Commercial Insurance		
HMO / PPO		
Legal Settlement		
Other		
None		

9. Please indicate up to five primary health problems that you are currently experiencing (use separate sheet for additional problems):

Health Problem	How long have you had this problem?	How severe is this?	How much does this interfere with your daily life?	How often does this interfere?
		<input type="checkbox"/> not a problem <input type="checkbox"/> mild problem <input type="checkbox"/> moderate problem <input type="checkbox"/> significant problem <input type="checkbox"/> very severe problem	<input type="checkbox"/> not at all <input type="checkbox"/> slightly <input type="checkbox"/> moderately <input type="checkbox"/> quite a bit <input type="checkbox"/> extremely	<input type="checkbox"/> none of the time <input type="checkbox"/> a little of the time <input type="checkbox"/> some of the time <input type="checkbox"/> most of the time <input type="checkbox"/> all of the time
		<input type="checkbox"/> not a problem <input type="checkbox"/> mild problem <input type="checkbox"/> moderate problem <input type="checkbox"/> significant problem <input type="checkbox"/> very severe problem	<input type="checkbox"/> not at all <input type="checkbox"/> slightly <input type="checkbox"/> moderately <input type="checkbox"/> quite a bit <input type="checkbox"/> extremely	<input type="checkbox"/> none of the time <input type="checkbox"/> a little of the time <input type="checkbox"/> some of the time <input type="checkbox"/> most of the time <input type="checkbox"/> all of the time
		<input type="checkbox"/> not a problem <input type="checkbox"/> mild problem <input type="checkbox"/> moderate problem <input type="checkbox"/> significant problem <input type="checkbox"/> very severe problem	<input type="checkbox"/> not at all <input type="checkbox"/> slightly <input type="checkbox"/> moderately <input type="checkbox"/> quite a bit <input type="checkbox"/> extremely	<input type="checkbox"/> none of the time <input type="checkbox"/> a little of the time <input type="checkbox"/> some of the time <input type="checkbox"/> most of the time <input type="checkbox"/> all of the time
		<input type="checkbox"/> not a problem <input type="checkbox"/> mild problem <input type="checkbox"/> moderate problem <input type="checkbox"/> significant problem <input type="checkbox"/> very severe problem	<input type="checkbox"/> not at all <input type="checkbox"/> slightly <input type="checkbox"/> moderately <input type="checkbox"/> quite a bit <input type="checkbox"/> extremely	<input type="checkbox"/> none of the time <input type="checkbox"/> a little of the time <input type="checkbox"/> some of the time <input type="checkbox"/> most of the time <input type="checkbox"/> all of the time
		<input type="checkbox"/> not a problem <input type="checkbox"/> mild problem <input type="checkbox"/> moderate problem <input type="checkbox"/> significant problem <input type="checkbox"/> very severe problem	<input type="checkbox"/> not at all <input type="checkbox"/> slightly <input type="checkbox"/> moderately <input type="checkbox"/> quite a bit <input type="checkbox"/> extremely	<input type="checkbox"/> none of the time <input type="checkbox"/> a little of the time <input type="checkbox"/> some of the time <input type="checkbox"/> most of the time <input type="checkbox"/> all of the time

10. What have you attempted to improve your health and wellness?
(yoga, health club, sports, herbal remedies, etc.)

Health / Wellness Activity	Benefit / Helpfulness
	<input type="checkbox"/> Not at all <input type="checkbox"/> A little bit <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit <input type="checkbox"/> Extremely
	<input type="checkbox"/> Not at all <input type="checkbox"/> A little bit <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit <input type="checkbox"/> Extremely
	<input type="checkbox"/> Not at all <input type="checkbox"/> A little bit <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit <input type="checkbox"/> Extremely
	<input type="checkbox"/> Not at all <input type="checkbox"/> A little bit <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit <input type="checkbox"/> Extremely
	<input type="checkbox"/> Not at all <input type="checkbox"/> A little bit <input type="checkbox"/> Moderately <input type="checkbox"/> Quite a bit <input type="checkbox"/> Extremely

11. Did you complete this survey:

<input type="checkbox"/> Independently	<input type="checkbox"/> With Assistance	<input type="checkbox"/> By Interview
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Comments: _____

**Thank you for completing this background information.
Please proceed to the SF-36 health questionnaire**

Health Maintenance Addendum

1. **Project Identification Number:** _____

2. **How long ago was your last face-to-face visit with a medical doctor or nurse practitioner?** (please use best unit of measurement; enter 0 if you have not received this service)

Days	Weeks	Months	Years

3. **How long ago was your last complete physical (exam & bloodwork)?** (please use best unit of measurement; enter 0 if you have not received this service)

Days	Weeks	Months	Years

4. **In maintaining your health, how helpful is your primary doctor?**

Extremely	Quite a bit	Moderately	Slightly	Not at all

5. **Using the *Male* or *Female* column, please indicate if (X) and when (mo./yr.) you had the following preventive health tests/measures:**

MALE	X	Mo./Yr.	FEMALE	X	Mo./Yr.
Blood pressure			Blood pressure		
Cholesterol			Cholesterol		
EKG– (heart rhythm)			EKG– (heart rhythm)		
Colorectal exam			Colorectal exam		
Blood sugar/diabetes			Blood sugar/diabetes		
Dental / oral exam			Dental / oral exam		
Eye / vision exam			Eye / vision exam		
Hearing exam			Hearing exam		
Prostate exam			Clinical breast exam		
			Mammogram		
			Pap smear		

**THE MOS 36-ITEM SHORT-FORM
HEALTH SURVEY (SF-36)**

INSTRUCTIONS: This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

(circle one)

- Excellent1
- Very Good2
- Good3
- Fair4
- Poor5

2. Compared to one year ago, how would you rate your health in general now?

(circle one)

- Much better now than one year ago1
- Somewhat better now than one year ago2
- About the same as one year ago3
- Somewhat worse now than one year ago4
- Much worse now than one year ago5

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

(circle one number on each line)

Activities	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
a. Vigorous activities , such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b. Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
c. Lifting or carrying groceries	1	2	3
d. Climbing several flights of stairs	1	2	3
e. Climbing one flight of stairs	1	2	3
f. Bending, kneeling, or stooping	1	2	3
g. Walking more than a mile	1	2	3
h. Walking several blocks	1	2	3
i. Walking one block	1	2	3
j. Bathing or dressing yourself	1	2	3

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

(circle one number on each line)

	YES	NO
a. Cut down on the amount of time you spent on work or other activities	1	2
b. Accomplished less than you would like	1	2
c. Were limited in the kind of work or other activities	1	2
d. Had difficulty performing the work of other activities (for example, it took extra effort)	1	2

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(circle one number on each line)

	YES	NO
a. Cut down the amount of time you spent on work or other activities	1	2
b. Accomplished less than you would like	1	2
c. Didn't do work or other activities as carefully as usual	1	2

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

(circle one)

- Not at all1
 Slightly2
 Moderately3
 Quite a bit4
 Extremely5

7. How much bodily pain have you had during the past 4 weeks?

(circle one)

- None1
 Very mild2
 Mild3
 Moderate4
 Severe5
 Very severe6

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

(circle one)

- Not at all1
- A little bit2
- Moderately3
- Quite a bit4
- Extremely5

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks -

(circle one number on each line)

	All of the time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
a. Did you feel full of pep?	1	2	3	4	5	6
b. Have you been a very nervous person?	1	2	3	4	5	6
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d. Have you felt calm and peaceful?	1	2	3	4	5	6
e. Did you have a lot of energy?	1	2	3	4	5	6
f. Have you felt downhearted and blue?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
i. Did you feel tired?	1	2	3	4	5	6

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with you social activities (like visiting with friends, relatives, etc.)?

(circle one)

- All of the time1
- Most of the time2
- Some of the time3
- A little of the time4
- None of the time5

11. How TRUE or FALSE is each of the following statements for you?

(circle one number on each line)

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. I seem to get sick a little easier than other people	1	2	3	4	5
b. I am as healthy as anybody I know	1	2	3	4	5
c. I expect my health to get worse	1	2	3	4	5
d. My health is excellent	1	2	3	4	5