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BAYLOR/TEXAS MEDICAL CENTER, HOUSTON CHILDREN'S HOSPITAL, DENVER CHILDREN'S HOSPITAL OF COLUMBUS CHILDREN'S HOSPITAL OF LOS ANGELES CHILDREN'S HOSPITAL & MEDICAL CENTER, SEATTLE CHILDREN'S HOSPITAL OF PHILADELPHIA CHILDREN'S HOSPITAL OF PITTSBURGH CHILDREN'S MEDICAL HOSPITAL, CHICAGO CHILDREN'S NATIONAL MEDICAL CTR., WASHINGTON DC DANA FARBER CANCER INSTITUTE, BOSTON EMORY UNIV. SCHOOL OF MEDICINE, ATLANTA MAYO CLINIC, ROCHESTER MD ANDERSON CANCER CENTER, HOUSTON CHILDREN'S MEDICAL CENTER, DALLAS CHILDREN'S HOSPITAL ANN ARBOR RILEY CHILDREN'S HOSPITAL, INDIANAPOLIS ST. JUDE CHILDREN'S RESEARCH HOSPITAL, MEMPHIS ST. LOUIS CHILDREN'S HOSPITAL STANFORD UNIV. SCHOOL OF MEDICINE, PALO ALTO UCLA MEDICAL CENTER, LOS ANGELES UCSF SCHOOL OF MEDICINE, SAN FRANCISCO UNIVERSITY OF ALABAMA, BIRMINGHAM UNIVERSITY OF MINNESOTA, MINNEAPOLIS UT-SOUTHWESTERN MEDICAL CENTER, DALLAS ROSWELL PARK, BUFFALO HOSPITAL FOR SICK CHILDREN, TORONTO

Long-Term Follow-Up Study

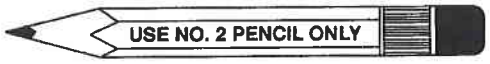
Person completing this questionnaire is _____
(Please print your full name)

If married, what is your maiden name _____

Today's date _____
(month/day/year)

Please follow these rules in completing this questionnaire. If you have any questions about completing this questionnaire, please call 1-800-775-2167.

1. Use the *No. 2 pencil enclosed* (Please do *not* use pen).



2. Completely darken your answers, that is, fill in the full circle.

CORRECT	INCORRECT
Ⓐ Ⓑ Ⓒ ●	⊗ ⊘ ◉ ◔

Written responses must stay within the boxes provided.

CORRECT	INCORRECT
grape	grape

3. Make no stray marks of any kind. Other than your responses, please keep the form as clean as possible. Erase cleanly any answer you wish to change. Do not use "white-out".


PLEASE DO NOT MARK IN THIS AREA

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A.1 What is your date of birth?

Write the numbers in the boxes. → Then fill in the matching circles. →

Month | Day | Year (1 9 _ _)

A.2 What is your sex?
- ○ Male
- ○ Female

A.3 What is your social security number?

– –

○ Do not have a social security number

A.4 To which one of the following groups do you belong?
- ○ White
- ○ Black
- ○ American Indian or Alaskan Native
- ○ Asian or Pacific Islander
- ○ Other *specify*

A.4a Are you Hispanic?
- ○ No
- ○ Yes

A.5 Are you a twin?
- ○ No → **Go to Question A.6**
- ○ Yes

A.5a If yes, which type of twin are you?
- ○ Identical
- ○ Fraternal (non-identical) same sex
- ○ Fraternal (non-identical) opposite sex
- ○ Not sure what type, same sex

A.6 Were you adopted?
- ○ No
- ○ Yes

A.7 How many full brothers and sisters (living or dead) do/did you have? Include only those brothers and sisters who have the same birth (biological) mother and father as you.

A.8 Please describe your current residence.
- ○ Single family dwelling - unattached (house)
- ○ Single family dwelling - attached (townhouse or condominium)
- ○ Apartment
- ○ Dormitory
- ○ Other *specify*

A.9 Concerning your current residence, do you:
- ○ Own your residence
- ○ Rent
- ○ Live with parents
- ○ Other *specify*

A.10 What is your current height without shoes? feet, and inches

A.11 What is your current weight without shoes? pounds

Medical Care

The next questions are about health care received during the 2 year period between January 1, 1994 and December 31, 1995.

B.1 Between January 1, 1994 and December 31, 1995 (2 year period), which of the following health care providers (excluding dentists) did you see or talk to for medical care? (Mark all that apply)

- ○ None → **Go to Question B.7, page 4**
- ○ Physician (including Osteopath)
- ○ Nurse
- ○ Chiropractor
- ○ Physical Therapist
- ○ Other *specify*

B.2 Where did you receive your health care? (Mark all that apply)

- ○ Doctor's office
- ○ Oncology (cancer) center or clinic
- ○ Other type of clinic
- ○ Hospital
- ○ Emergency Room or Urgent Care Center
- ○ Other *specify*

B.3 During this 2 year period, how many times did you see a physician?

- ○ 0 times
- ○ 1 - 2 times
- ○ 3 - 4 times
- ○ 5 - 6 times
- ○ 7 - 10 times
- ○ 11 - 20 times
- ○ More than 20 times

B.4 During this 2 year period, how often did you telephone a doctor's office, regarding an illness or a medical condition you may have had?

- ○ 0 times
- ○ 1 - 2 times
- ○ 3 - 4 times
- ○ 5 - 6 times
- ○ 7 - 10 times
- ○ 11 - 20 times
- ○ More than 20 times

B.5 During this 2 year period, how many times were you admitted to any hospital?

B.6 During this 2 year period (January 1, 1994 to December 31, 1995), did you have any operations or surgeries?

- ○ No
- ○ Yes

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B.7 On these 2 pages, we would like to know about medicines/drugs you have taken during the 2 year period between January 1, 1994 and December 31, 1995. We are interested in medicine/drugs which you have taken consistently for more than one month, or for a total of 30 days in one year. Please list only those drugs prescribed by your doctor and filled by a pharmacist. Include pills, syrups, injections, patches, creams.

Please do NOT list medicine/drugs that you buy off the shelf at the drug store (over the counter drugs).

	No	Yes	Not sure
1. ANTIBIOTICS such as amoxicillin, bactrim, erythromycin, penicillin or others	○	○	○
If yes, specify the name of the drug(s).			
2. BIRTH CONTROL PILLS such as Demulen, Lo-ovral, Loestrin, Norinyl, Norplant, Ortho-Novum, Ovral, Triphasil or others	○	○	○
If yes, specify the name of the drug(s).			
3. ESTROGENS OR PROGESTERONES (FEMALE HORMONES) such as Estrace, Estraderm patch, Premarin, Provera, Medroxyprogesterone or others	○	○	○
If yes, specify the name of the drug(s).			
4. TESTOSTERONES (MALE HORMONES) such as Delatesteral, Testosterone cypionate, enanthate or others	○	○	○
If yes, specify the name of the drug(s).			
5. THYROID MEDICATIONS such as L-thyroxin, Levothyroid, Levothyroxin, Synthroid or others	○	○	○
If yes, specify the name of the drug(s).			
6. OTHER MEDICINES TO REPLACE BODY HORMONES such as prednisone, DDAVP (Desmopressin), hydrocortisone, growth hormones or others	○	○	○
If yes, specify the name of the drug(s).			
7. MEDICATION FOR DIABETES such as Insulin, Diabinase, Glucotrol, Micronase, Orinase, Tolinase or others	○	○	○
If yes, specify the name of the drug(s).			
8. MUSCLE RELAXANTS such as Baclofen, Flexeril, Valium, Chlorzoxazone (Paraflex) or others	○	○	○
If yes, specify the name of the drug(s).			
9. PRESCRIBED PAIN MEDICINES such as Tylenol with Codeine (Tylenol #3), Ansaid, Disalcid, Feldene, Fiorecet or others	○	○	○
If yes, specify the name of the drug(s).			
10. PRESCRIBED NUTRITIONAL SUPPLEMENTS such as Ferrous Sulfate (Iron), Magnesium, Potassium, Bicitra (Sodium Bicarbonate), Phosphorus (NutraPhos), Vitamin D (Rocalcetrol) or others	○	○	○
If yes, specify the name of the drug(s).			

Not sure
Yes
No

11. **ANTI-EPILEPTIC (ANTI-SEIZURE) DRUGS such as Dilantin, Phenobarbital, Depakane, Tegretol (Carbamazepine), Klonipen, Primidone (Mysoline), Zarontin or others** ..... ○○○

If yes, specify the name of the drug(s):

12. **DRUGS FOR HIGH BLOOD PRESSURE OR FOR YOUR HEART such as Atenolol (Tenoretic), Captopril, Digoxin (Lanoxin), Lasix (Furosemide), Inderal, Methyl-Dopa, Dyazide (Triamterene), Procardia, Vasotec or others** ..... ○○○

If yes, specify the name of the drug(s):

13. **PRESCRIBED ANTACIDS (for excess stomach acid or ulcers) such as Tagamet (Cimetidine), Zantac (Ranitidine), Pepsid (Famotidine) or others** ..... ○○○

If yes, specify the name of the drug(s):

14. **CHEMOTHERAPY/IMMUNE SUPPRESSANTS such as Cytoxan, Immuran, Prednisone, Ifosfamide or others** ..... ○○○

If yes, specify the name of the drug(s):

15. **ANTIDEPRESSANTS OR OTHER PRESCRIBED DRUGS FOR DEPRESSION OR OTHER MOOD DISORDERS such as Elavil, Prozac, Paxil, Zoloft, Navane, Ritalin or others** ..... ○○○

If yes, specify the name of the drug(s):

16. **OTHER PRESCRIBED DRUGS** ..... ○○○

If yes, specify the name of the drug(s) and reason(s) for use:

B.8 At the present time, do you have any of the following?

	No	Yes
Persistent hair loss	○	○
Scarring or disfigurement of the head or neck region (including the face)	○	○
Scarring or disfigurement of the chest or abdomen region	○	○
Scarring or disfigurement of the arms or legs (including an abnormally short arm or leg)	○	○
Walk with a limp	○	○
Loss of an arm, leg, finger or toe	○	○
Loss of an eye	○	○
Other	○	○

specify

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Medical Conditions

The next series of questions relate to medical conditions that have ever occurred in your lifetime.

Please indicate, by filling in the circle (either "No", "Yes", or "Not sure") if a doctor or other health care professional has told you that you have any of the following conditions. In addition, please give your approximate age when you were first told about this condition. (If more than one occurrence, please give age at first time.)

Because we need definite responses, it is very important to mark an answer for each question, even if you have never had that condition. Please do not leave any questions blank (unmarked).

Some questions require a number as well as an answer. Write your answer in the boxes provided and fill in the corresponding circles.

Example

	Not sure	Yes	No	If yes, age at first occurrence? (Years)
G.1 Hay fever?	○	●	○	
G.2 Recurrent sinus infections or sinus surgery?	○	○	●	6

HEARING/VISION/SPEECH

Have you ever been told by a doctor or other health care professional that you have, or have had...

	Not sure	Yes	No	If yes, age at first occurrence? (Years)
C.1 Hearing loss requiring a hearing aid?	○	○	○	
C.2 Deafness in one or both ears not completely corrected by hearing aid?	○	○	○	
C.3 Complete deafness in either ear?	○	○	○	
C.4 Tinnitus or ringing in the ears?	○	○	○	
C.5 Persistent dizziness or vertigo?	○	○	○	
C.6 Problems hearing sounds, words, or language in crowds?	○	○	○	
C.7 Any other hearing problems?	○	○	○	

If yes, describe this problem.

C.8 Legally blind in one or both eyes?	○	○	○	
C.9 Cataracts?	○	○	○	
C.10 Glaucoma (excess pressure in the eyeball)?	○	○	○	
C.11 Problems with double vision?	○	○	○	

Have you ever been told by a doctor or other health care professional that you have, or have had...

	Not sure	Yes	No	If yes, age at first occurrence? (Years)
C.12 A detached retina or any other condition of the retina?	○	○	○	

If yes, describe this problem.

C.13 Any other trouble seeing with one or both eyes even when wearing glasses?	○	○	○	
C.14 Very dry eyes requiring eye drops or ointment?	○	○	○	
C.15 Any other eye problems?	○	○	○	

If yes, describe this problem.

C.16 Stammering or stuttering?	○	○	○	
C.17 Any other speech defects?	○	○	○	

If yes, describe this defect.

C.18 Abnormal sense of taste?	○	○	○	
C.19 Loss of taste or smell which has lasted for 3 months or more?	○	○	○	

URINARY SYSTEM

D.1 Kidney stones?	○	○	○	
D.2 REPEATED kidney infections?	○	○	○	
D.3 REPEATED bladder infections?	○	○	○	
D.4 Dialysis?	○	○	○	
D.5 Any other kind of kidney or urinary tract disorder?	○	○	○	

If yes, describe this disorder.

Remember, it is very important that you mark an answer for each of the following questions, even if you have never had that condition.

Have you ever been told by a doctor or other health care professional that you have, or have had...

If yes, age at first occurrence? Not sure / Yes / No — Years

HORMONAL SYSTEMS

E.1 An overactive thyroid gland (hyperthyroid)? ..... ○○○ ☐
E.2 An underactive thyroid gland (hypothyroid)? ..... ○○○ ☐
E.3 Thyroid nodules? ..... ○○○ ☐
E.4 Other thyroid enlargements? ..... ○○○ ☐

E.5 Diabetes - that is controlled with diet? ..... ○○○ ☐
E.6 Diabetes - controlled with pills or tablets? ..... ○○○ ☐
E.7 Diabetes - controlled with insulin shots? ..... ○○○ ☐
E.8 Deficiency of growth hormone? ..... ○○○ ☐

E.9 Have you ever received injections of growth hormone (Protropin or Humatrope)? ..... ○○○ ☐
E.10 Osteoporosis, brittle, weak or fragile bones? ..... ○○○ ☐
E.11 Did you need medication to go into puberty? ..... ○○○ ☐
E.12 Any other hormonal problems? ..... ○○○ ☐

If yes, describe this problem.

E.13 Has a doctor ever told you that you might have trouble having children? ..... ○○○ ☐
E.14 Have you ever had medical tests (such as a blood test, an ultrasound, or sperm count) to see whether or not you might have trouble having children? ..... ○○○ ☐

Females - → Go to Question E.16

E.15 MALES - Have you ever been told you had a low sperm count? ..... ○○○ ☐

Males - → Go to Question F.1

Have you ever been told by a doctor or other health care professional that you have, or have had...

If yes, age at first occurrence? Not sure / Yes / No — Years

E.16 FEMALES - Have you ever had a menstrual period? ..... ○○○ ☐

If no, → Go to Question F.1

E.17 FEMALES - Are you currently having menstrual periods? ..... ○○○

If no, at what age was your last menstrual period? ☐

E.18 Have you ever taken female hormones, including birth control pills (oral contraceptives) to have your period? ..... ○○○ ☐

HEART AND CIRCULATORY SYSTEM

F.1 Rheumatic heart disease? ..... ○○○ ☐
F.2 Hardening of the arteries or arteriosclerosis? ..... ○○○ ☐
F.3 Irregular heartbeat or palpitations, (Arrythmia) requiring medication or follow-up by a doctor? ..... ○○○ ☐
F.4 Congestive heart failure or cardiomyopathy (weak heart muscle)? ... ○○○ ☐

F.5 A myocardial infarction (heart attack)? ..... ○○○ ☐
F.6 Coronary heart disease? ..... ○○○ ☐
F.7 Hypertension (high blood pressure) NOT requiring medication? ..... ○○○ ☐
F.8 Hypertension (high blood pressure) requiring medication? ..... ○○○ ☐

F.9 A stroke or a cerebrovascular accident? ..... ○○○ ☐
F.10 Angina pectoris (chest pains due to lack of oxygen to heart requiring medication such as nitroglycerine)? ..... ○○○ ☐
F.11 Pericarditis or fluid around the heart? ..... ○○○ ☐
F.12 Pericardial constriction (scarring or tightness of the sac around the heart)? ..... ○○○ ☐

F.13 Stiff or leaking heart valves? ..... ○○○ ☐
F.14 Heart catheterization ("heart cath")? ..... ○○○ ☐
F.15 Biopsy of the heart muscle? ..... ○○○ ☐

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