Baylor Advancing Sequencing into Childhood Cancer Care (BASIC^3 Study) Questionnaire

This questionnaire is part of a study at Texas Children's Hospital/Baylor College of Medicine which is designed to understand the best way to introduce large-scale DNA sequencing tests into the care of childhood cancer patients.

This questionnaire will ask many questions about your health.

All the information you provide will be kept strictly confidential.

In this questionnaire please answer all questions about yourself.

Name_____
Last First Middle (Maiden)

Date of Birth:_____

Place of Birth: _____
City/Country State/Province Country

Because we are receiving federal support for research and are applying for more federal support, we need to know your race and ethnicity. In order to collect these data, we request that you provide the following information.

Please complete **BOTH** Section 1 **and** Section 2:

SECTION 1

Do you consider yourself to be Hispanic, Latino or of Spanish Origin (Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race)?

- □ Hispanic, Latino, or of Spanish origin.
- □ Not Hispanic, Latino, or of Spanish origin.

SECTION 2

What race do you consider yourself to be? Please select **one or more** of the following:

- □ *American Indian or Alaska Native* - A person having origins in any of the original peoples of North, Central, or South America, and who maintains tribal affiliations or community attachment.
- □ *Asian* - A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, The Philippine Islands, Thailand, and Vietnam. (Note: Individuals from the Philippine Islands have been recorded as Pacific Islanders in previous data collection strategies)
- □ *Black, or African American* – A person having origins in any of the black racial groups of Africa.
- □ *Native Hawaiian or Other Pacific Islander* – A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.
- □ *White* – A person having origins in any of the original peoples of Europe, the Middle East, or North Africa
- □ Check here if you do not wish to provide some or all of the above information.

It is also helpful to know if you are from a specific ethnic group
(for example, Amish, Ashkenazi or Sephardic Jewish)?

□ No □ Don't know

□ Yes, please specify: _____

Please list all of your medical problems:

Condition	Date Diagnosed

Please list all of your current medications:

Please list all of your hospitalizations and the reason for hospitalization:

Date of hospitalization	Reason

Please list all of your surgeries and the reason for your surgery:

Date of surgery	Reason

Have you ever smoked at least 100 cigarettes (5 packs) in your lifetime?

- ☐ No
- ☐ Yes, quit smoking
- ☐ Yes, currently smoking

If yes, how old when you began smoking? _____years old

About how many years did you smoke? _____years

On average, how many cigarettes smoked per day? #_____

Have you ever drunk alcoholic beverages at least once a week, for one year or more?

- ☐ No
- ☐ Yes, but quit
- ☐ Yes, currently

If yes, how many drinks per week on average? _____

How many years has the pattern of drinking been like this? _____years

The next section is about conditions that are very rare. Many are diagnosed at birth. Please check whether a doctor or other health professional has ever diagnosed you with the following conditions.

		Year Diagnosed
<u>Brain or Nervous System, such as</u>		
Hydrocephalus (water on the brain)	□ Yes □ No □ Don't know	_____
Myelomeningocele (Spina Bifida)	□ Yes □ No □ Don't know	_____
Developmental Delay	□ Yes □ No □ Don't know	_____
Psychiatric problem_____	□ Yes □ No □ Don't know	_____
Stroke	□ Yes □ No □ Don't know	_____
Other_____	□ Yes □ No □ Don't know	_____
<u>Face or Head, such as</u>		
Cleft Lip	□ Yes □ No □ Don't know	_____
Cleft Palate	□ Yes □ No □ Don't know	_____
Both	□ Yes □ No □ Don't know	_____
Microcephaly (small head)	□ Yes □ No □ Don't know	_____
Other_____	□ Yes □ No □ Don't know	_____
<u>Eye, such as</u>		
Aniridia (absence of colored part of the eye)	□ Yes □ No □ Don't know	_____
Heterochromia (two different colored eyes)	□ Yes □ No □ Don't know	_____
Cataracts	□ Yes □ No □ Don't know	_____
Conjunctival telangiectasia	□ Yes □ No □ Don't know	_____
Other_____	□ Yes □ No □ Don't know	_____
<u>Endocrine system, such as</u>		
Pituitary disorder_____	□ Yes □ No □ Don't know	_____
Diabetes		
Type 1 (juvenile onset)	□ Yes □ No □ Don't know	_____
Type 2 (adult onset)	□ Yes □ No □ Don't know	_____
Adrenal disease_____	□ Yes □ No □ Don't know	_____
Other_____	□ Yes □ No □ Don't know	_____
<u>Heart or Circulatory System, such as</u>		
Atrial/Ventricular Septal Defect (hole in the heart)	□ Yes □ No □ Don't know	_____
Abnormal Valves	□ Yes □ No □ Don't know	_____
Transposition (crossed arteries)	□ Yes □ No □ Don't know	_____
Hypertension(high blood pressure)	□ Yes □ No □ Don't know	_____
Thrombosis (clot in vessel)	□ Yes □ No □ Don't know	_____
Hemorrhage location_____	□ Yes □ No □ Don't know	_____
Arteriovenous malformation	□ Yes □ No □ Don't know	_____
Hemangioma	□ Yes □ No □ Don't know	_____
Other_____	□ Yes □ No □ Don't know	_____

		Year Diagnosed
Muscle or bone, such as		
Extra fingers	□ Yes □ No □ Don't know	_____
Missing fingers	□ Yes □ No □ Don't know	_____
Extra toes	□ Yes □ No □ Don't know	_____
Missing toes	□ Yes □ No □ Don't know	_____
Deformed limb	□ Yes □ No □ Don't know	_____
Club foot	□ Yes □ No □ Don't know	_____
Hemihypertrophy (one side of body larger than other)	□ Yes □ No □ Don't know	_____
Short stature	□ Yes □ No □ Don't know	_____
Abnormal bones on xray	□ Yes □ No □ Don't know	_____
Other_____	□ Yes □ No □ Don't know	_____
Skin, such as		
Café-au-lait spots	□ Yes □ No □ Don't know	_____
Extra nipples	□ Yes □ No □ Don't know	_____
Axillary freckling (freckles under armpits)	□ Yes □ No □ Don't know	_____
Birthmark Type_____	□ Yes □ No □ Don't know	_____
Rash	□ Yes □ No □ Don't know	_____
Blistering	□ Yes □ No □ Don't know	_____
Sensitivity to sunlight	□ Yes □ No □ Don't know	_____
Eczema	□ Yes □ No □ Don't know	_____
Other_____	□ Yes □ No □ Don't know	_____
Renal system, such as		
Cystic kidneys	□ Yes □ No □ Don't know	_____
Absent kidney	□ Yes □ No □ Don't know	_____
Extra kidney	□ Yes □ No □ Don't know	_____
Blockage of the kidney	□ Yes □ No □ Don't know	_____
Blockage of the bladder	□ Yes □ No □ Don't know	_____
Other_____	□ Yes □ No □ Don't know	_____
Gastrointestinal system, such as		
Pyloric stenosis (blockage of stomach outlet)	□ Yes □ No □ Don't know	_____
Tracheoesophageal fistula (connection between windpipe and esophagus)	□ Yes □ No □ Don't know	_____
Pancreatic insufficiency	□ Yes □ No □ Don't know	_____
Gallstones	□ Yes □ No □ Don't know	_____
Other_____	□ Yes □ No □ Don't know	_____

				Year Diagnosed
Reproductive system, such as				
Hypospadias (abnormal urethral opening)	□ Yes	□ No	□ Don't know	_____
Undescended testicle(s)	□ Yes	□ No	□ Don't know	_____
Absent or malformed ovaries	□ Yes	□ No	□ Don't know	_____
Absent or malformed uterus	□ Yes	□ No	□ Don't know	_____
Miscarriages or stillbirths	□ Yes	□ No	□ Don't know	_____
Other_____	□ Yes	□ No	□ Don't know	_____
Hereditary Syndromes, such as				
Rothmund-Thomson Syndrome	□ Yes	□ No	□ Don't know	_____
Fanconi's anemia	□ Yes	□ No	□ Don't know	_____
Beckwith-Wiedemann syndrome	□ Yes	□ No	□ Don't know	_____
Cowden's disease	□ Yes	□ No	□ Don't know	_____
Gardner's Syndrome (Multiple polyposis of the colon)	□ Yes	□ No	□ Don't know	_____
Peutz-Jegher's Syndrome	□ Yes	□ No	□ Don't know	_____
Neurofibromatosis (von Recklinghausen's disease)				
Type I	□ Yes	□ No	□ Don't know	_____
Type II	□ Yes	□ No	□ Don't know	_____
Nevoid basal cell carcinoma syndrome	□ Yes	□ No	□ Don't know	_____
Sturge-Weber syndrome	□ Yes	□ No	□ Don't know	_____
Tuberous sclerosis	□ Yes	□ No	□ Don't know	_____
Turcot's syndrome	□ Yes	□ No	□ Don't know	_____
MEN I (Wermer's syndrome)	□ Yes	□ No	□ Don't know	_____
MEN II (Sipple's syndrome)	□ Yes	□ No	□ Don't know	_____
Von Hippel-Lindau disease	□ Yes	□ No	□ Don't know	_____
Xeroderma pigmentosa	□ Yes	□ No	□ Don't know	_____
Bloom Syndrome	□ Yes	□ No	□ Don't know	_____
Werner Syndrome	□ Yes	□ No	□ Don't know	_____
Ataxia-telangiectasia	□ Yes	□ No	□ Don't know	_____
Gorlin Syndrome	□ Yes	□ No	□ Don't know	_____
Chromosome abnormalities, such as				
Trisomy 21 (Down Syndrome)	□ Yes	□ No	□ Don't know	_____
Trisomy 13 (Patau's Syndrome)	□ Yes	□ No	□ Don't know	_____
Trisomy 18 (Edward's Syndrome)	□ Yes	□ No	□ Don't know	_____
Klinefelter's Syndrome (XXY)	□ Yes	□ No	□ Don't know	_____
Turner's Syndrome (XO)	□ Yes	□ No	□ Don't know	_____
Other_____	□ Yes	□ No	□ Don't know	_____

Has a doctor or other health professional ever diagnosed you with cancer or a tumor?

□ Yes □ No

- If no, skip this section and go to the next page
- If yes, please answer the following questions:

Type of cancer_____

Date of diagnosis_____

Type of therapy (provide as much information as you know):

□ Surgery

Type of surgery: _____
Date of surgery: _____
Place of surgery_____
Name of surgeon_____

□ Chemotherapy

Length of treatment_____
Names of chemotherapy drugs
_____
_____
_____
_____
Place of treatment_____
Name of treating physician_____

□ Radiation Therapy

Length of radiation treatment_____
Total amount of radiation (if known)_____cGy
Place of treatment_____
Name of radiation oncologist_____

The questions in this section ask you to tell us how good you are working with different types of math and whether you prefer to use numbers or words to explain things.

For each of the following questions, please check the box that best reflects how good you are at doing the following things:

1. How good are you at working with fractions?

☐1 ☐2 ☐3 ☐4 ☐5 ☐6

Not at all good **Extremely good**

2. How good are you at working with percentages?

☐1 ☐2 ☐3 ☐4 ☐5 ☐6

Not at all good **Extremely good**

3. How good are you at calculating a 15% tip?

☐1 ☐2 ☐3 ☐4 ☐5 ☐6

Not at all good **Extremely good**

4. How good are you at figuring out how much a shirt will cost if it is 25% off?

☐1 ☐2 ☐3 ☐4 ☐5 ☐6

Not at all good **Extremely good**

For each of the following questions, please check the box that best reflects your answer:

5. When reading the newspaper, how **helpful** do you find tables and graphs that are parts of a story?

☐1 ☐2 ☐3 ☐4 ☐5 ☐6

Not at all helpful **Extremely helpful**

6. When people tell you the chance of something happening, do you prefer that they use **words** ("it rarely happens") or **numbers** ("there's a 1% chance")?

☐1 ☐2 ☐3 ☐4 ☐5 ☐6

Always Prefer Words **Always Prefer Numbers**

7. When you hear a weather forecast, do you prefer predictions using **percentages** (e.g., “there will be a 20% chance of rain today”) or predictions using only **words** (e.g., “there is a small chance of rain today”)?

☐1 ☐2 ☐3 ☐4 ☐5 ☐6

Always Prefer Percentages **Always Prefer Words**

8. How **often** do you find numerical information to be useful?

☐1 ☐2 ☐3 ☐4 ☐5 ☐6

Never **Very Often**

The following questions ask about your current understanding of genetics.

Please indicate whether the following statements are true or false.

	True	False
9. Healthy parents can have a child with an inherited disease	□	□
10. If close relatives have diabetes/heart disease, you are more likely to develop these	□	□
11. The carrier of a disease gene may be completely healthy	□	□
12. If a person is the carrier of a disease gene it means that they have the disease	□	□
13. Having increased genetic risk means you get that disease regardless of what you do	□	□
14. Living a healthy lifestyle will not make any difference if you have an increased genetic risk for a disease	□	□
15. Genetic tests can be done to find out how a person will react to certain drugs	□	□
16. Most genetic disorders are caused by a single gene	□	□
17. People who have a genetic marker for a disease are unhealthy	□	□
18. Your blood can uniquely identify you because it contains your DNA	□	□

The questions in this section are designed to learn about your preferences for making decisions about your child's care. Please rate the importance of the following statements, from Very Important to Not at all Important.

In making decisions about my child's care, it is important to me that…	**Very Important**	**Important**	**Not very Important**	**Not at all Important**
19. My thoughts are taken into account just as much as the considerations of my doctor	☐	☐	☐	☐
20. There is enough time for questions	☐	☐	☐	☐
21. My child's doctor and I weigh up the different treatment options thoroughly	☐	☐	☐	☐
22. I am able to discuss the different treatment options with my child's doctor in detail	☐	☐	☐	☐
23. My child's doctor and I select a treatment option together	☐	☐	☐	☐
24. I know the advantages of the individual treatment options	☐	☐	☐	☐
25. I know which treatment option is the best one for my child	☐	☐	☐	☐
26. I feel included in the treatment decision	☐	☐	☐	☐
27. I feel jointly responsible for my child's further treatment	☐	☐	☐	☐
28. My child's doctor and I discuss the next steps of the treatment plan in detail	☐	☐	☐	☐
29. My child's doctor and I reach an agreement as to how we will proceed	☐	☐	☐	☐

30. Check the box next to the phrase below that best describes the role you have actually taken <u>with your child's doctor</u> in dealing with your child's healthcare.
    - ☐ I prefer to make the final selection about which treatment my child will receive.
    - ☐ I prefer to make the final selection of my child's treatment after seriously considering my child's doctor's opinion.
    - ☐ I prefer that my child's doctor and I share responsibility for deciding which treatment is best for my child.
    - ☐ I prefer that my child's doctor makes the final decision about which treatment will be used, but seriously considers my opinion.
    - ☐ I prefer to leave all decisions regarding my child's treatment to my child's doctor.

31. Check the box next to the phrase below that best describes the role you have actually taken <u>with your child</u> in dealing with your child's healthcare.
    - ☐ I prefer to make the final selection about which treatment my child will receive.

- ☐ I prefer to make the final selection of my child's treatment after seriously considering my child's opinion.
- ☐ I prefer that my child and I share responsibility for deciding which treatment is best for my child.
- ☐ I prefer that my child makes the final decision about which treatment will be used, but seriously considers my opinion.
- ☐ I prefer to leave all decisions regarding my child's treatment to my child.

The next set of questions ask some general information about you and your family

32. What is your sex?
    - ☐ Male
    - ☐ Female

33. Are you now married, widowed, divorced, separated, never married or living with a partner?
    - ☐ Married
    - ☐ Widowed
    - ☐ Divorced
    - ☐ Separated
    - ☐ Never married
    - ☐ Living with partner

34. How many living children do you have?

    _____

    34b. How many of your living children are younger than 18 years old?

    _____

    34c. How many of your living children are adopted?

    _____

35. What is the highest level of education you completed?
    - ☐ None
    - ☐ Grade school (grades 1 to 8)
    - ☐ Some high school (grade 9-12)
    - ☐ High school graduate or GED
    - ☐ Post high school training other than college (vocational, technical, etc.)
    - ☐ Some college or associates degree
    - ☐ College graduate
    - ☐ Master's degree
    - ☐ Doctoral degree

36. As of today, what is your employment status? Please check all that apply.
    - ☐ Employed more than or equal to 32 hours/week
    - ☐ Employed less than 32 hours/week
    - ☐ Employed, but on medical leave
    - ☐ Full-time student
    - ☐ Part-time student
    - ☐ Unemployed, seeking work
    - ☐ Homemaker
    - ☐ Unable to work due to disability
    - ☐ Retired

37. What is your area of occupation?
    - ☐ Business, Financial, Management, Sales and Related Occupations
    - ☐ Computer, Engineering and Mathematical Science
    - ☐ Life, Physical, and Social Science
    - ☐ Legal
    - ☐ Education, Training, and Library

- ☐ Arts, Design, Entertainment, Sports, and Media
- ☐ Healthcare Practitioner
- ☐ Office and Administrative Support
- ☐ Construction, Maintenance, and Natural Resources
- ☐ Production and Transportation
- ☐ Other – Please specify: _____

38. What was the total income (before taxes) from all sources within your household in the last year? Please select one.
    - ☐ Less than $10,000
    - ☐ $10,000 to $19,999
    - ☐ $20,000 to $34,999
    - ☐ $35,000 to $49,999
    - ☐ $50,000 to $74,999
    - ☐ $75,000 to $99,999
    - ☐ $100,000 to $149,999
    - ☐ $150,000 or more

Thank you for taking time to complete this questionnaire.