

Thank you for taking the time to complete our *5p- Minus Family Questionnaire*. This questionnaire is concerning your child with cri du chat syndrome. The questionnaire was developed with the input from family members, professionals working in the field of cri du chat syndrome, and from reviewing other questionnaires. The *5p- Minus Family Questionnaire* is distributed by Dr. Dennis Campbell, chair of the 5p- Society Professional Advisory Board.

We are currently updating the **5p Minus' data base**. The information provided by you will be gathered to increase and update the database on the syndrome. Through the database, we hope to learn more about cri du chat syndrome, support ongoing research, identify commonalities among , provide teacher and providers common characteristics, program needs, and areas of concern. Each year we are encouraged that this information will lead to better educational programming. Also the discussion of what types, intensity, and strategies of both educational and related services that are provide to our children which will result in better learner outcomes. In addition, please feel free to add additional information if the allotted space is inadequate, **OR** is there is more information that you think needs to be shared.

If you choose to complete the questionnaire, please answer and provide information to the best of your ability. If you are not quite sure or uncertain about a question, answer as best as you can or answer "**UN**"-*Unsure*. The reason is because it is important to know the difference between something you **forgot to answer** and one that you simple were **unsure of whether that question applied to your child**.

If your response is that you are unsure how it applies to your child, or you do not understand a question, or know how to complete the requested information, then your response would be **unsure** so please mark "**UN**"-*Unsure*.

If question asked does not apply to your child or you child does not have that specific medical complication, then your response would be **not applicable** so please mark "**NA**"—*Not Applicable*.

Please let us remind you that your participation in answering and providing information in this questionnaire is entirely **voluntary**. Although we do encourage all families to complete the questionnaire, failure to participate will in no way jeopardize your relationship with the **5p Minus Society**.

Assessment of Communicative Abilities of Individuals with Cri-du-chat Syndrome  
Family History Questionnaire

**PARENT/GUARDIAN INFORMED CONSENT**

You are invited to participate in a study of the individuals with Cri-du-chat syndrome. Specifically we hope to identify the patterns of individual's behavior and education plans. We hope this information will help us identify appropriate educational goals. The study is to be conducted by Dr. Dennis Campbell at the University of South Alabama, and Dr. AmySue Reilly at Auburn University. The study is gathering information about communication and language abilities, overall development, and behavior of young children with Cri-du-chat. We are looking for individuals with Cri du chat of any age.

If you are interested in participating please contact Dr. Campbell, or Dr. Reilly. We will send a packet of information for you to complete. We will also like to encourage families who have participated in the past to provide updated information on your children. If you have questions, contact Dr. Dennis Campbell (251) 380 2877 [campbell@usouthal.edu](mailto:campbell@usouthal.edu) ; or Dr. AmySue Reilly (334) 844 2110 [reillam@auburn.edu](mailto:reillam@auburn.edu) ; we will be happy to answer your questions.

If you agree to participate please type in your full name below.

Signature

Today's date

Relationship to Child with Cri du Chat

Address:

City:

State/Providence:

Zip/ Postal Code:

Telephone:

**INSTRUCTIONS**

Thank you for choosing to complete the **5p Minus Family Questionnaire**, please answer and provide information to the best of your ability. In order be sure that you did not forget to answer or skip a question, we have provided two additional response options. For the drop down forms simply highlight your choice.

If your response is that you are unsure how it applies to your child, or you do not understand a question, or know how to complete the requested information, then your response would be **unsure** so please mark **“UN”-Unsure**.

If question asked does not apply to your child or you child does not have that specific medical complication, then your response would be **not applicable** so please mark **“NA”—Not Applicable**.

**FAMILY INFORMATION**

Child’s Last Name:

First Name:

Child’s Date of Birth

Child’s Place of Birth:

Child’s birth Father’s Name:

Child’s birth Father’s Age at Child’s Birth:

Child’s birth Mother’s Name:

Child’s birth Mother’s Age at Child’s Birth:

**For the Mother:**

The total numbers of pregnancies that you have had are

The total number of children that you have:

This child’s birth was the (First, second, etc) pregnancy:

This child is your (First, second, etc) child:

**Please list brothers, sisters, and stepchildren in order of their ages beginning with oldest child:**

Name	gender	birth date
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Marital status

Are you and your spouse actively engaged in counseling related to having a child with a disability?

Are other family members involved with counseling related to having a sibling with a disability?

Does your child with cri du chat live with:

If another relative please indicate type of relative:

Other residence

Number of other residents

### **SPECIFIC BIRTH INFORMATION**

*We ask these questions to learn as much as possible about circumstances of the birth. There is no indication that any action, or lack of action, causes the birth of a child with cri du chat syndrome.*

Were any genetic tests performed pre-birth (CVS, amino)?

Reason for Testing:

Was ultrasound performed during pregnancy?

If yes, were any abnormalities noted?

If yes, please describe:

Were there any unusual problems with the pregnancy?

If yes, please describe:

Did the mother take any medication during pregnancy?

If yes, please name or describe type of medication:

Any difficulties/ complications with delivery?

If yes, please describe:

Child was born at how many weeks:

Child's weight: e.g. 6 lbs. 7 oz.

Child's length: in inches

Child's head circumference: inches

Did child go to:

If other please describe.

Did the doctor's suspect cri du chat syndrome at birth?  
Child's age when diagnosed with cri du chat syndrome:

Initial diagnosis based on: clinical features consistent with the syndrome  
or features were not present but chromosome studies revealed 5p abnormality

Type of chromosome abnormality:

If a translocation, which parent is a carrier?

Do other family members carry a translocation?  
If yes Who

Is there anyone else in the family with Cri du chat syndrome?  
*If yes, relationship to child*

*List full karyotype if known (i.e. 46, XX, del(5)(p14.2):*

### **CLINICAL FEATURES**

*There are many physical features that are frequently associated in children with cri du chat syndrome. Some of these features may also be shown in children who do not have cri du chat syndrome. If you don't know if your child had any of these features please check "don't know."*

At birth or infancy my child had: (check all that apply)

High pitched cry

Skin tags (extra pieces of skin, usually around the ears)

Small head (microcephaly)

Low-set or unusual ears

Poor muscle tone (hypotonic)

Tight muscles (hypertonic)

Feeding difficulties

Seizures

Note anything else you find relevant:

**MEDICAL HISTORY**

**Has testing or evaluation been done on your child's:**

**Eyes:**

If yes describe the problem

Corrective action:

**Ears/ hearing:**

If yes describe the problem

Corrective action:

**Teeth/gums:**

If yes describe the problem

Corrective action:

**Mouth/jaw:**

If yes describe the problem

Corrective action:

**Heart:**

If yes describe the problem

Corrective action:

**Nose/ Sinuses:**

If yes describe the problem

Corrective action:

**Lungs:**

If yes describe the problem

Corrective action:

**Vocal cords/ larynx:**

If yes describe the problem

Corrective action:

**Throat/tonsils:**

If yes describe the problem

Corrective action:

**Digestive systems:**

If yes describe the problem

Corrective action:

**Urinary tract/ kidneys:**

If yes describe the problem

Corrective action:

**Sex organs:**

If yes describe the problem

Corrective action:

**Orthopedic:**

If yes describe the problem

Corrective action:

**Neurologic:**

If yes describe the problem

Corrective action:

Other: Please describe:

My child has had:

- Recurring ear infections
- Recurring cold hands and feet
- Recurring gagging and choking
- Drooling past age one
- Constipation

If answered yes to any of the above, please describe:

Has your child reached puberty?

If yes: what age (in years) did you detect    underarm hair                      pubic hair

Males:                      growth in genitalia                      facial hair

Females:                      breast development                      menstruation (periods)

Please note any other specific changes associated with puberty:



### **MEDICATION HISTORY**

Has your child been on any medication for a medical reason or behavioral reason other than normal childhood illness?

If yes, for each medication, describe the medication, what it was used to treat and when it was required.

### **SURGERY HISTORY**

If not described previously, list any medical procedures or surgeries that were performed.

### **ALTERNATIVE MEDICINE**

Other than traditional medicine, has your child been exposed to other forms of treatments (acupuncture, herbal remedies, food supplements, etc.)? If so please describe what was used, the reason for the treatment and whether the treatments were/ are successful.

### **OTHER COMMENTS**

Please add any additional comments that you think may be relevant to cri du chat syndrome:

If you would like to print a copy for yourself.