

Speech-Language and Feeding Consultation Parent Questionnaire

Child's Name	Parent/Care Giver
Date of Birth	E-mail
Age	Address
Gender	Telephone
Date	Country

Speech-Language History

Does your child use gestures to communicate?

Does your child use sign language to communicate?

Does your child use an augmentative communication system? If so, please describe.

At what age did your child babble?

At what age did your child speak his or her first word?

At what age did your child began combining words in phrases or sentences?

Approximately how many words does your child say?

How long are his or her sentences?

Did your child ever stop talking for a period of time? If so, please describe.

How much does your child understand?

How much of your child's speech do you understand?

How much of your child's speech do unfamiliar listeners understand?

Does your child have a cleft palate?

If so, was it surgically repaired?

Does your child enjoy interacting with others in a nonverbal fashion?

Does your child point to or show you things he or she wants?

How does your child respond when you point to or show him or her things?

Describe your child's eye contact.

Describe your child's attention span.

Describe how your child reacts when he or she is unable to communicate wants or needs.

Do you have concerns about your child's pronunciation skills? (If so, please describe.)

Do you have concerns about your child's language skills? (If so, please describe.)

Has your child been diagnosed with autism?

Has your child been diagnosed with sensory integration difficulties?

Educational History

What is your child's grade in school?

Describe any therapy or assistance your child receives. Include the amount of therapy (e.g., 2 times per week for 30 minute sessions) and the ages at which therapy began and ended.

Speech-language therapy

Occupational therapy

Physical therapy/Physiotherapy

Special education program

Aide in the classroom

Other

Medical History

Describe your child's overall health.

Describe any significant illnesses your child has experienced, including the ages.

Describe any surgeries your child has had, including the ages.

Describe any medications your child takes, including dosages.

Does your child have any limb malformations? (Please describe)

Does your child have a history of any heart conditions?

Which of the following has your child had? How often does this occur?

Colds

Sinusitis

Pneumonia

Ear infections

Asthma

Hoarse voice

Vomiting

Allergies (describe)

Fevers

Gastroesophageal reflux or GERD

Blepharitis

Seizures

Other

Have you had genetic testing?

If so, what were the findings?

Feeding History

Do you think your child drinks normal amounts of liquids?

Do you think your child eats a normal amount of food at mealtimes?

Does your child like to snack during the day? If so, how often?

What types of food does your child currently eat?

What types of food, if any, does your child refuse to eat?

Does your child eat most table foods?

What modifications, if any, do you make to your child's meals?

Does your child eat solid foods? (Provide examples.)

Does your child eat pureed foods? (Provide examples.)

Does your child drink liquids? (Provide examples.)

From a bottle

From a sippy cup

From a regular cup

From a straw

Does your child drink thickened liquids?

What modifications, if any, do you make to your child's beverages?

Does your child experience difficulty

Biting

Chewing

Swallowing

What size bites does your child take?

Is your child a messy eater?

Is your child a picky eater?

Is your child a slow eater?

Is your child a fast eater?

Does your child enjoy mealtime?

Do you enjoy mealtime with your child?

During or after feeding, does your child

Make unpleasant faces

Choke

Cough

Gag

Spit food out

Stuff food in his or her mouth

Have a gargly sounding voice

Cry

Vomit

Refuse to eat

Is your child tube fed?

Has your child ever been tube fed? If so, when?

Has your child ever had feeding therapy?

Was the feeding therapy conducted by a speech-language pathologist?

Has your child ever had a swallow study conducted?

If so, what type of study was conducted?

What were the results?

Has your child ever had a GI study?

What were the findings?

What utensils do you use to feed your child?

What utensils does your child use to feed himself or herself?

Is there anything else that you think you should mention with regard to your child's feeding history or feeding difficulties?

What do you hope to obtain from the feeding consultation?

Do I have your permission to include this information in research involving feeding or speech-language development in children with CdLS? No names or other identifying information associated with your child will be used in any presentations or publications of the findings, except photos and genetic test results (i.e., only the specific gene associated with your child's diagnosis of CdLS), and **only if you agree**. The **only** reason a photograph of your child might be shared, with your permission, is to link the physical characteristic of CdLS that your child demonstrates, to the nature of the speech, language, and feeding difficulties he or she exhibits, to determine a clinical profile. With your permission, Dr. Kline, a geneticist and Medical Director of the CdLS Foundation, also might see the photos of your child, as she is collaborating with me on this research project.

Your permission has no bearing on whether or not your child receives a speech, language, or feeding consultation. Please initial each of the following, for which you grant permission:

_____ Yes, I give my permission for the information from my child's speech-language and feeding consultation to be included in professional research presentations and publications.

_____ No, I do not give my permission to participate in a research study.

PHOTOGRAPHS:

_____ Yes, I give permission for photographs of my child's or, in the case of an adult, my face and arms and hands to be taken so that the physical features of CdLS can be compared to any speech, language, and feeding difficulties.

_____ Yes, I give my permission for these photographs to be shared with Dr. Kline.

_____ Yes, I give my permission for these photographs to be shared at future professional conferences, such as the CdLS conference. I understand that no names will be included.

_____ Yes, I give my permission for these photographs to be published in professional journals, such as the *American Journal of Medical Genetics*, regarding the speech, language, and feeding issues of individuals with CdLS. I understand that no names will be included.

_____ No, I do not give permission for photographs of me or my child to be taken or used for any purpose.

GENETIC TEST RESULTS (NIPBL, HDAC8, SMC1A, SMC3, and RAD21):

_____ Yes, I give my permission for my child's or my genetic test results to be compared to the findings regarding any speech, language, or feeding difficulties.

_____ Yes, I give my permission for these results to be shared with Dr. Kline.

_____ Yes, I give my permission for these results to be shared at future professional conferences, such as the CdLS conference. I understand that no names will be included.

_____ Yes, I give my permission for these results to be published in professional journals, such as the *American Journal of Medical Genetics*, regarding the speech, language, and feeding issues of individuals with CdLS. I understand that no names will be included.

_____ No, I do not give my permission to have my child's or my genetic test results used in a research study.

Signature of Parent or Guardian (or self, in the case of an adult)

Date

Thank you very much for your input. It truly is appreciated. If you have any questions, you may contact me directly at 630-617-3196 (office), 630-617-6461 (fax), cheric@elmhurst.edu, or through the Cornelia de Lange Syndrome Foundation office. Questionnaires may also be sent to:

Cheri S. Carrico, Ph.D., CCC-SLP
Professor and Undergraduate Program Director
Communication Sciences and Disorders
Elmhurst College
190 Prospect Avenue
Elmhurst, IL 60126

Clinical Advisory Board, National Cornelia de Lange Syndrome Foundation
Scientific Advisory Council, International Cornelia de Lange Syndrome Association

Informed Consent Form for Adults, Parents, and Caregivers

Project Title: Speech, Language, and Feeding Issues in Individuals with Cornelia de Lange Syndrome (CdLS)

Introduction of Researcher

I am Dr. Cheri Carrico, Director of the Undergraduate Program in the Department of Communication Sciences and Disorders at Elmhurst College. I also am a member of the Clinical Advisory Board of the National Cornelia de Lange Syndrome Foundation and a member of the Scientific Advisory Council of the International Cornelia de Lange Syndrome Association. Should you have questions at any time about this project, please feel free to contact me at Dr. Cheri S. Carrico, Speech-Language-Hearing Clinic, Elmhurst College, 190 Prospect Ave., Elmhurst, IL 60126, USA; or at (630) 617-3196; or at cheric@elmhurst.edu.

Purpose of Research

I am conducting a study of the speech, language, and feeding issues found in individuals with Cornelia de Lange syndrome. I would appreciate your participation in this study, as it will assist us in further identifying the characteristics associated with the speech, language, and feeding concerns of individuals with CdLS and in providing appropriate treatment.

Explanation of Procedures

You will be completing a questionnaire that takes approximately 15 - 20 minutes to complete. In addition, with your permission, photographs may be taken or requested. For individuals attending the conference, the study will run for the duration of the CdLS conference; all individuals seeking a speech, language, or feeding consultation will be asked to complete the same questionnaire. In addition, your specific speech, language, and feeding issues and concerns will be addressed during your consultation appointment. For those individuals who would like to participate in the study but are not attending the national conference, you will be asked to complete the same questionnaire and send photographs, if you are comfortable. Any questions or concerns you have will be addressed via e-mail communication, or you may telephone Dr. Carrico at 630-617-3196 (USA).

Risks and Benefits

I do not anticipate any foreseeable risks or discomfort other than the inconvenience to you in completing the questionnaire. Although this study may not directly benefit you, it potentially will benefit individuals affected by CdLS and those who treat and care for them. If you request assistance with feeding techniques, the individual with CdLS may experience coughing, choking, gagging, vomiting, sensory discomfort, or food aversion, similar to what he or she might experience during oral feeding of a typical meal, when given food or a beverage.

Safeguards of Data

No code numbers or letters will be used to identify you, except during the data analyses. Data will be published in aggregate form and may be presented at

professional meetings, such as occurred at this conference, or published in professional journals. Data will be kept in a file in the investigator's office. The data will be destroyed at the conclusion of the study.

Freedom to withdraw from the study

Your participation is completely voluntary. If you choose to withdraw from the study, the information gathered at that point will be destroyed, and you will not be penalized (i.e., you will still receive the speech-language or feeding consultation you requested).

Third Party Referral

If you have any complaints about your treatment as a participant in this study, please write the chair of the Institutional Review Board: Ms. Elaine Fetyko Page, Research Review Board, Elmhurst College, 190 Prospect Avenue, Elmhurst, IL 60126 or e-mail her at elainep@elmhurst.edu. Although Ms. Page will ask your name, all complaints are kept in confidence.

Closing

I have received an explanation of the study and agree to participate. I understand that my participation in this study is strictly voluntary, and that I may withdraw at any time.

Signature

Date

This research project has been approved by the Elmhurst College Institutional Review Board (IRB).

Assent Form for Child/Minor

I, _____, understand that my parents (Mom and Dad) have given permission (said it's okay) for me to take part in a project about speech, language, and feeding being done by Dr. Carrico. I am taking part because I want to. I have been told that I can stop any time I want to and nothing will happen to me if I want to stop.

Signature of participant and date