Cleft Palate - Craniofacial Pre-Clinic Appointment Questionnaire

Dear Parents

Thank you for completing this short questionnaire. Your responses will help our team prepare for your child’s next appointment with our Cleft Palate Craniofacial Team.

Goal of Team Interview Questions:

To hear family's concerns and help the team to respond to these concernsTo identify current community resources available to youTo help families access other resources available (e.g. to assist with COVID impact).To help determine if any additional specialists are requiredTo help families and team determine which of our team's services are necessary now, and to help plan for essential in-person appointments when clinics are allowed to resumeTo provide findings and recommendations for our weekly team triage meeting.To save and return to your survey, please remember to copy down your unique Code following clicking "Save & Return Later".

Questionnaire Consent: BCCH CLEFT PALATE CRANIOFACIAL PROGRAM - PREPARING FOR YOUR CHILD'S NEXT APPOINTMENT

You are invited to complete this survey because we want to help families and our care team determine which of our team's services are necessary for your child's upcoming in-person and/or "virtual" appointment, determine if any additional specialists are required, identify current community resources available to you, help families access other resources (to assist with COVID-19 impact), and provide findings and recommendations for our care team's weekly triage meetings. As caregivers of patients of the Provincial Health Services Authority (PHSA), you are invited to complete in this survey by Dr. Christine Loock. Questions about your information and this survey, or withdrawing your consent may be directed to Dr. Loock, Medical Director, Cleft Palate Craniofacial Program cloock@cw.bc.ca or Sandra Robertson, RN, Care Coordinator srobertson@cw.bc.ca or Kathryn Urquhart, Social Worker kurquhart2@cw.bc.ca.

The information you provide in this questionnaire will significantly improve the quality and efficiency of your child's team assessment, however you may answer as many or as few questions as you are comfortable with. There will be no penalties if you do not want to complete this survey. It will take less than 30 minutes to complete the survey and we would like you to complete the survey at least two days before your scheduled appointment. Your survey responses will be reviewed by the BCCH Cleft Palate Craniofacial team in preparation for your child's appointment and a copy of your survey responses will be added to your child's medical record.

Your personal information is also protected by our privacy law in BC (called the Freedom of Information and Protection of Privacy Act (FIPPA)). We will only use your information for the purposes listed on this form. In this survey you will be asked to share the following information for use by PHSA:

Personal views/opinions expressed in this survey. Your name and the name of your child Personal health-related information and diagnosis. If you have documents/records your wish to share, they may be uploaded in the survey Date of birth Phone number(s) Your personal email address Personal Health Number Postal Code Photographs if requested (please check email). May include identifiable features. Photos may be uploaded in the survey We are asking you to provide a personal email address so that we can communicate with you about this survey and your participation. Before you provide your consent, please carefully consider whether this email account is secure, whether other people have access to it or whether you have concerns about the security of any information sent to this account. We will only send your personal information to the email address you have provided to us, and all of the information which you provide to us will be kept confidential. However, you should be aware that some webmail services (e.g. Gmail, Hotmail, etc.) may store the contents of your email account outside of Canada (for example, in the United States), where privacy and data security standards may be different than they are in Canada. The security of information sent over the internet can also not be guaranteed. The email communications we exchange with you may contain some of your personal information (your name, health information, etc.). Under FIPPA, we require your consent in order to send your personal information outside of Canada. By providing your email address in this informed consent form, you are voluntarily providing your consent for the study team to communicate with you using your email account.

Only the BCCH Cleft Palate – Craniofacial team and the technical support team at BCCH Research Institute will access your child's information. The BCCH Cleft Palate - Craniofacial team will run the survey and analyze the results. Survey data including any photographs and files uploaded will be stored in the PHSA's BC Children's Hospital Research Institute's Secured Network electronically for no more than one year. A copy of your survey responses, files and photographs will be added to your child's medical chart. A copy of our team's clinical report and follow-up recommendations will be given to you (via my e-health, postage mail, or e-mail) and to your child's designated care provider(s).

Consent

I have read and understand this form. I voluntarily consent to PHSA collecting, using, and disclosing the information I provide as a survey participant. Your consent is implied when you complete this survey.

◯ I consent (please click "Next page" and proceed to survey) ◯ I do not consent (please exit from survey)

Personal Information and Consent

Who is completing this questionnaire?	_____
Name of Patient	_____
Guardian/Parent Name:	_____
Birth Date	_____
Current Age	_____
E-mail	_____
Phone Number(s) (indicate best number for contact)	_____
Personal Health Number (PHN)	_____
Postal Code	_____
Are you able to consent for us to schedule a phone/virtual and/or in-person appointment if needed?	◯ Yes ◯ No
I/We have read the PHSA Digital Communications Form and consent to communicating our child's personal health information via e-mail and other digital means.	◯ Yes ◯ No
Digital* Appointment Preferences	☐ Phone ☐ Zoom ☐ Other (e.g. Facetime) ☐ None ((*Note: Digital communication includes the use of email, phone, text, video conference and any other form of electronic transmission used to send patient information or facilitate an exchange of information between Providers and Patients.))
Other	_____

Your Child's Care Team

Community Family Doctor/Nurse Practitioner / Walk-in Clinic	_____
Community Pediatrician	_____
Plastic Surgeon	_____
ENT	_____
Dentist	_____
Orthodontist	_____
Speech/Hearing Supports	_____
Other active specialists	_____

What Matters to You?

What are the things that are important to you at this moment as it pertains to care in our program and what would you like to achieve as part of planning for an in-person and/or 'distanced virtual' assessment?

_____

What can we do today to best support you in your child's care in our program?

_____

Has anyone else from our team been helping you and your child outside of team meetings?

- ☐ Nurse Care Coordinator
- ☐ Pediatricians
- ☐ Plastic Surgery
- ☐ ENT
- ☐ Dental/Orthodontic/Oral Surgery
- ☐ Other Specialists
- ☐ SLP Therapy and other Services
- ☐ Hearing Services & Supports
- ☐ Social Services/Special Needs Supports
- ☐ Not applicable

Other Specialists

_____

Review of Systems (including Medications, Allergies, and Immunizations):

Your child's height: _____

Your child's weight: _____

Medications: (list here or upload a list below) _____

Medications: (option to attach list)

Last Flu shot (year): _____

Last Immunizations (list type and year here or upload a list below): _____

Immunization record: (option to attach list)

Allergies to medicines/environment: (list here or upload a list below) _____

Allergies to medicines/environment: (option to attach list)

Is your child currently waiting for any surgery that has been postponed due to COVID-19?
◯ Yes
◯ No

General Health (Pediatrics)

Any concerns about your child's growth:	☐ Height ☐ Weight ☐ Other ☐ No
Please describe	_____
Any concerns about your child's development, learning, or school progress	◯ Yes ◯ No
Please describe	_____
Any concerns about your child's social emotional well being?	◯ Yes ◯ No
Please Describe	_____
Any concerns about your child's socialization/bullying	◯ Yes ◯ No
Please describe	_____
Any concerns about your child's mental health (mood, anxiety, attention)	◯ Yes ◯ No
Please describe	_____
Family History of similar conditions	◯ Yes ◯ No
Please describe here or upload a summary below if possible:	_____
Option to attach a summary	
Does your child need a referral for psychoeducational support and diagnosis?	◯ Yes ◯ No
Would you like a referral or follow-up consultation for more information regarding recurrent risks or possible environmental or genetic associations to your child's health?	◯ Yes ◯ No

Since COVID-19, any difficulties accessing services for your child?	◯ Yes ◯ No
Please describe	_____
Do you have other questions or concerns about your child's general health or diagnoses?	_____
Social supports: Do you have enough help caring for your child/youth's?	◯ Yes ◯ No ◯ Not applicable

Audiology (Hearing)

Do you have any concerns at this time about your child's hearing?	◯ Yes ◯ No
Please describe	_____
When did your child last have a hearing test?	_____
What was the result of this test?	_____
Does your child use hearing aids?	◯ Yes ◯ No
Do you have other specific questions or concerns for audiology?	_____

Speech and Language

Do you have any concerns about your child's speech or language development?	◯ Yes ◯ No
Please describe	_____
Is it hard for you to understand what your child is saying?	◯ Yes ◯ No
Is it hard for others to understand what your child is saying?	◯ Yes ◯ No
Does your child's speech sound "hyper-nasal", like sound is coming through their nose?	◯ Yes ◯ No
Does your child always sound like their nose is plugged or congested?	◯ Yes ◯ No
Do you have other specific questions or concerns for SLP?	_____

ENT (Ear Nose Throat)

Ears: Do you have any concerns about your child's ears other than hearing e.g. pain, itchiness, drainage, etc?	◯ Yes ◯ No
Please describe	_____
When was your child last seen by ENT (Doctor's name and date)	_____
Nose: Does your child have any difficulty breathing through their nose or other symptoms, like discharge or bleeding?	◯ Yes ◯ No
Sleep: Does your child have any breathing difficulties when they sleep?	◯ Yes ◯ No
Sleep: Any other concerns regarding sleep (i.e. bedtime routines, etc)?	◯ Yes ◯ No
Please describe	_____
Do you have other specific questions or concerns for ENT?	_____

Facial Appearance and Function (Plastic Surgery/Craniofacial)

Do you or your child have any concerns about their facial appearance or function, including basic activities required for daily living (like eating, communicating, and social functions)?

◯ Yes
◯ No

Please describe

_____

Does food or fluid come out of your child's nose while eating or drinking?

◯ Yes
◯ No

When was your child last seen by a plastic surgeon? (Doctor name and date)

_____

Is your child waiting for a craniofacial, cleft, jaw or hand surgery?

◯ Yes
◯ No

Do you have other specific questions or concerns for plastic surgery?

_____

Orthodontics and Dentistry

Do you have basic concerns about oral health and hygiene?	◯ Yes ◯ No
Do you have any concerns about their teeth or bite?	◯ Yes ◯ No
Please describe	_____
When was your child last seen by a dentist? (Dentist name and time)	_____
When was your child last seen by an orthodontist? (Orthodontist name and time)	_____
Is your child currently undergoing orthodontic treatment such as wearing orthodontic appliances or retainer?	◯ Yes ◯ No
Please describe the treatment: what is being worn and how long it has been in place.	_____
Do you have other specific questions or concerns for orthodontics/dentistry?	_____

Social History & Supports Due to COVID Impact - April 2020

"Pediatric health care providers should take a social history during all patient encounters to better identify core social determinants impacted by the COVID-19 pandemic, inquiring about income, food and housing security, safety, social support, access to services and medications and (other) risk factors ....." -Suleman, Ratnani, Loock et al. Canadian Pediatric Society, 2020 https://www.cps.ca/en/documents/position/what-paediatricians-can-do-to-support-children-and-youth-during-the-covid-19

Has anything changed for your family since COVID began?	◯ Yes ◯ No
Social Capital: How many people can you call on for help during this time if you needed more support?	◯ More than 20 ◯ Between 9-20 ◯ Between 5 to 8 ◯ Less than 5
Economic Security: "Have you had any difficulty making ends meet?"	◯ Yes ◯ No
Access to food: "Are you having trouble getting the right food for your family?"	◯ Yes ◯ No
Access to housing: "Are you concerned about having a stable and safe place to live?"	◯ Yes ◯ No
Employment changes: "Has COVID had any effect on your employment?"	◯ Yes ◯ No

If yes, how?

_____

Photos of your child's face & teeth (8 photos in total)
Face - front view (smiling, serious, or goofy) whatever you can get
Face - front view (no smile with lips closed)
Face - side view (no smile with lips closed)
Wide smile with teeth showing - front view only
Inside the mouth - lower teeth
Inside the mouth - upper teeth
Normal bite (teeth showing), with top & bottom teeth together in a relaxed way - front view. The lips will have to be pulled back to show their full bite
Normal bite (teeth showing), with top & bottom teeth together in a relaxed way - side view. The lips will have to be pulled back to show their full bite

Closing

Do you have any other unspoken concerns or questions you want to highlight?

_____