

# **An environmental scan of cleft lip and palate clinics and dental benefit programs in Canada**

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### **List of Abbreviations**

BCCH – British Columbia Children’s Hospital  
CDCP – Children’s Dental Care Program  
CDHP – Children’s Dental Health Program  
CHEO – Children’s Hospital of Eastern Ontario  
CL/P – Cleft Lip with or without Cleft Palate  
CLP – Cleft Lip and Palate  
CLP/C – Cleft Lip and Palate / Craniofacial  
CP – Cleft Palate  
CPT – Cleft Palate Team  
DHP – Dental Health Plan  
IWK – Isaac Walton Killiam Health Sciences Centre  
MCP – Medical Care Plan  
MHCS – Manitoba Health services Commission  
MoHLTC – Ministry of Health and Long Term Care  
MSI – Medical Services Insurance  
MSP – Medical Services Plan  
MTAP – Medical transportation Assistance Program  
NAM – Nasoalveolar Moulding  
NHSN – Northern Health Services Network  
NHTG – Northern Health Travel Grant  
NIHB – Non Insured Health Benefits  
NPTP – Northern Patient Transportation Program  
NSHSC – Nova Scotia Hearing and Speech Centres  
OAC – Operational Advisory Committee  
OHIP – Ontario Health Insurance Plan  
QSI – Quikard Solutions Inc.  
SLP - Speech Language Pathologist  
SPCC – Specialized Paediatric Coordinating Council  
TVCC – Thames Valley Children’s Centre  
VIHA – Vancouver Island Health Authority

## Executive Summary

Cleft lip with or without cleft palate (CL/P) and cleft palate (CP) are two of the most frequently occurring birth defects in Canada, affecting between 400 and 500 newborns every year<sup>(1)</sup>. The incidence of infants born with CL/P and CP has remained relatively constant from 1996-2004. However, the net increase in population due to natural growth and the increase in the population of ethnic and racial groups, which have been shown to have higher prevalence rates of orofacial clefts, may be an indication of an increasing number of new cases of CL/P and CP, in the future.

There are 21 cleft lip and palate (CLP) clinics operating across Canada. These clinics vary in size, organization and function. They range from well-known large clinics in tertiary care centres, where all services are provided through an outpatient clinic, to less familiar small clinics operating in regional hospitals that provide follow-up and referral services. Some teams are strictly CLP teams, some are also craniofacial teams, whereas others are CLP teams that are a part of a craniofacial team and either function jointly or distinctly from the craniofacial team. This scan is primarily intended as a guide to oral cleft care clinics and programs; but not necessarily craniofacial programs.

All provinces and territories manage specific programs that cover dental services for the treatment of CLP. The manner in which provinces implement the programs and allocate funding for dental services varies extensively. More importantly, there are considerable discrepancies regarding the types of treatment services covered and the extent of coverage. As a result, patients and their families in one province may face significant out of pocket costs for the same dental treatment that may be completely insured in another province.

All CLP clinical programs in Canada are essentially paediatric programs. Orofacial clefts are repaired with a high rate of success; this is especially true when treatment is initiated at infancy or as early in life as possible. Children are normally followed by a multidisciplinary CLP or craniofacial teams until early adulthood. Most CLP teams report that, in some cases, dental problems can, and do, persist into adulthood for a number of reasons. The severity and extent of complications in adults is unknown as there are no available follow-up data once patients are discharged from the programs.

Dental expenditures related to orofacial cleft treatment continue to escalate as more expensive treatment modalities, such as dental implants and nasoalveolar molding (NAM), are becoming more common practice. NAM, normally performed by an orthodontist in the first 3-4 months following birth, reduces the severity of the cleft deformity, improves nasal aesthetics and potentially may result in healthcare cost savings by reducing the need for secondary surgical procedures and alveolar bone grafts<sup>(28,29,42)</sup>. Despite the improvement in treatment outcomes and potential savings in future

medical costs, the cost of NAM is either borne by the parents and/or the provincial cleft palate dental programs.

The Ontario Cleft Lip and Palate/Craniofacial (CLP/C) Program is a model of organization and centralization. Ontario is one of only two provinces that maintains a provincial registry of CLP/C patients. Patients are identified at birth and registered immediately thereafter in a hospital setting or through a formal referral process. One delegated "paymaster" for all seven CLP/C centres is responsible for all billing functions. A standardized provincial web-based database is utilised to capture all patients registered with the program, collect data for all dental treatment plans submitted and calculate the amount of funding expended by each of the centres.

## Conclusions and Recommendations

Our Scan of provincial and territorial cleft lip and palate dental programs revealed a wide degree of variation in the provision of insured services. Large discrepancies in the rationing of dental services for congenital craniofacial conditions between jurisdictions, is a strong contention in favour of the coordination of public financed dental care policy in Canada. Cumulative research suggests that individuals with oral clefts are at an increased risk for developing psychosocial problems (34). Harmonization and standardization of insured dental services would go a long way in ensuring that all children with oral clefts in Canada have equal access to affordable dental treatment with favourable outcomes, and prospects of a healthy social life.

Some programs, such as Manitoba's Cleft Lip and Palate/Dysplasia Program, provide exceptional dental benefits while other programs appear appreciably underfunded. As a minimum, cleft palate dental programs should insure 100% of the cost of orthodontic treatment, oral surgery and periodontal procedures related to a cleft of the hard palate. In addition, full coverage should apply to any restorative dentistry necessitated for the correction of congenitally malformed teeth and/or the cost of a removable partial denture to replace congenitally missing teeth. A few provinces and territories already provide more than this minimal coverage, however, most do not. Infant orthopaedic treatment and appliances, including nasoalveolar moulding are "medically necessary" and "medically required" procedures that go hand in hand and significantly influence the success of plastic surgery. Furthermore, because of the potential savings to the health care system in the way of fewer surgical procedures for the infant/child (28,29,42), orthopaedic appliances and treatment should be considered "medically insured" procedures, despite the fact that the most qualified providers of this therapy are dental specialists.

Our scan also made evident that most provinces do not maintain a provincial registry of CLP/C patients. Some programs only register patients after the first dental claim submission has been received. More surprising was the fact that several cleft palate teams found it difficult to derive the number of new patient registrations, in their respective clinics, in recent years. The advantages of a provincial registry that enrolls new patients from as early as birth are threefold. Firstly, registries enable incidence surveillance on a provincial and, cumulatively, on a national level. Secondly, they facilitate the tracking of patients, completed services and costs. Last of all, registries permit the prediction of dental costs in future years.

Most cleft palate teams that responded to our survey reported that, in some cases, dental problems can, and do, persist into adulthood. It is not uncommon for teams to receive phone calls and emails from adults with CLP looking for treatment and/or funding support. This finding corroborates

reports that we received from About Face International, an advocacy group on behalf of those touched by facial difference. Recent reports in the dental literature also support the assertion that complications and patient satisfaction are an issue in adulthood (35-38). The severity and extent of problems in adults is unknown as there is no available follow-up data once patients are discharged from the paediatric programs. Clearly, investigation in this area is required as indications point to a need for adult care. This could eventually call for the development of parallel adult components to the cleft palate programs that are in existence today. The current paediatric programs are based on the growth and development needs of young patients; whereas, the needs of adult patients would be related to optimizing function and oral health.

## **Scan Objectives**

This scan of Canadian CLP programs has four objectives. Firstly, this report will identify and provide contact information for the cleft palate clinics that are functioning across Canada. All teams that are operating in Canada are included in our review and not only teams that have applied for approval to be listed as American Cleft Palate-Craniofacial Association/Cleft Palate Foundation approved teams. Secondly, this report will give an account of each CLP team's organization and activity based on the number of active patients, annual new patient registrations, and brief description of team composition and operations. There is no judgment or statement of quality made about any of the established teams. Clearly, large tertiary care centres have more resources; however, smaller regional teams also coordinate treatment and provide invaluable services to patients with oral clefts and their families. The third objective of this report is to describe, for every jurisdiction, the dental benefit programs that are available to patients with cleft palate, and disclose the annual expenditures for funding these programs. The fourth objective is to determine what services are available for adults and how adult patients with ongoing treatment concerns are managed by the health care facilities.

The report is intended to act as an informative reference guide for patients, families, health care providers and policy makers. Furthermore, it is meant to assist cleft palate teams in uncovering where other cleft palate teams operate and what dental treatment coverage is available in other jurisdictions. Information such as this will enable health care providers to accurately advise relocating families and patients, as well as contact members of other cleft palate teams for professional consultation. In addition, this report describes the utilization statistics for patients receiving dental treatment benefits for CLP and the cost of funding these programs in each province. A compilation of such information may ultimately prove useful to medical and dental advocates as a tool for comparison, and for maintaining and/or expanding cleft palate programs within their own authority. To our knowledge, information regarding all CLP teams in Canada and all provincial and territorial CLP dental benefit programs has never been compiled in a single review package.



## Introduction

Cleft lip with or without cleft palate (CL/P) and cleft palate (CP) are two genetically distinct variations of oral facial clefts caused by abnormal facial development during gestation. In Canada, approximately 400 to 500 babies are born each year with a CL/P or CP (1). The national incidence rate of CL/P and CP has remained relatively constant. Between 1996 and 2004, the Canadian Congenital Anomalies Surveillance System reported that the annual incidence of CL/P ranged from 8.7 to 11.1 cases per 10,000 births, while the annual incidence for CP ranged 6.5 to 8.2 cases per 10,000 births (2).

### Epidemiology of CL/P and CP and Canadian Population Growth

Oral cleft prevalence rates vary depending on race and ethnicity. In their extensive review of prevalence and incidence data, Mossey and Little (2000) concluded that geographical variation is more apparent for CL/P than for CP and that migrant groups retain rates of CL/P similar to those of their area of origin (3). Epidemiological studies consistently show that compared to Whites, African Americans have lower prevalence of CL/P and CP (4-9). Research has also consistently demonstrated that Native Americans experience higher prevalence of CL/P and CP (9-13). At 3.74 per 1000 live births, the prevalence of orofacial clefts recorded in the First Nations people of British Columbia is among the highest in the world (14).

High prevalence rates of CL/P among certain Asian groups were reported in the past (14,15). Murray et al (1997) reported a prevalence of 1.94 per 1000 live births in the Philippines (16). Nevertheless, research on oral cleft prevalence rates of Asians as compared to Whites has been inconsistent. In a study conducted in Hawaii in 1974, Ching and Chung reported higher prevalence of CL/P in Asians (Chinese, Filipinos, and Japanese) compared to Whites (17). However, in 1998 using data from a very large and diverse population in California, Croen et al. (1998) reported that the prevalence of CL/P and CP for Chinese, Filipinos and Japanese were similar to the prevalence among Whites, and lower for Koreans (9). Interestingly, the same study showed a higher prevalence rate for CP for those of East Indian origin as compared to Whites. In general, prevalence results between studies should not be compared because the incidence of orofacial clefts reported to occur among races and ethnic groups is a gross estimate based on different sources of information, sample size, time of diagnosis, classification of clefts, degree of clinical delineation and inclusion of stillbirths and abortions in the base population (18). In addition, Tolarova and Cervenka (1998) suggested that differences in prevalence in earlier studies may be influenced by dissimilar methods for ascertainment, such that many cases that are now diagnosed as syndromic, and are therefore excluded, were included in previous studies (19).

According to Statistics Canada, the number of births in Canada swelled from over 337,000 in 2003/04 to over 377,000 in 2008/09, or nearly 12% (20). So remarkable has been this rise, that the net increase of population due to natural growth, the number of deaths subtracted by the number of births,

which peaked in 1991 and began to decline, reversed the downward trend in 2004. Arguably due to economic prosperity and social benefit programs aimed at families, it was Alberta and Quebec that showed the largest percentage gain in births and increases in birth rates. In addition, as highlighted in a 2005 Statistics Canada report, the Aboriginal population is expected to grow at an average annual rate of 1.8%, more than twice the rate of 0.7% for the general population (21).

Despite the recent increase in natural growth, Canada's population growth is derived primarily through immigration, which accounts for approximately two-thirds of the total population increase. As a matter of fact the face of country is rapidly changing. Statistics Canada recently reported that one in six Canadians is a visible minority with that ratio set to increase to one in five by the year 2017, if the current trend in immigration continues (23). The rise in visible minorities is attributed to the high level of immigrants who have recently entered the country from non-European countries. At one time, most immigrants to Canada were arriving from Europe; however, in recent years immigration is derived primarily from South Asia (24). From 2005 to 2007 the four main countries of immigrant origin have been China and Hong Kong, India, Philippines and Pakistan (25).

In summary, the net increase in population due to natural growth may be an indication of an increasing number of reported new cases of CL/P and CP, in the future. Moreover, this rising trend may be further bolstered by the growing size of sub-populations that have been demonstrated to have higher prevalence rates of orofacial clefts.

## **Patient Care**

Cleft palate care continues to evolve. During the first half of the 20<sup>th</sup> century surgeons and dentists started to work more closely together in order to restore speech and function. Specifically, it was the secondary deformities of the surgical techniques of the day that necessitated the provision of corrective dental therapy. Collapse of the maxilla due to tension was a common complication following surgical closure of clefts involving the lip, palate and alveolar process, which resulted in anterior crowding and malocclusion (39). In turn, this necessitated the services of orthodontists to align teeth and dentists to extract anterior overcrowded teeth and fabricate dentures that could occlude properly over the lower incisors (41). To be sure, the significance of prosthodontic management of patients with oral clefts can not be overstated. The American Cleft Palate–Craniofacial Association, which was founded in 1943, was in fact originally named the American Academy of Cleft Prosthesis (40). It was not until 1950 that Christopher Kerr McNeil, a Scottish orthodontist, introduced the concept of early orthodontic treatment by preparing the alveolar arch prior to cheiloplasty using acrylic plates fixed to extraoral attachments (43). McNeil further advocated for the closest possible cooperation between plastic surgeon and dental specialist (39).

Today orofacial clefts are repaired with a high rate of success and in less time due to better surgical and orthodontic management. This is especially true when treatment is initiated at infancy or as early in life as possible. Children with orofacial clefts are normally followed by a multidisciplinary cleft palate or craniofacial team that monitors speech, dental development, hearing impairment and psychosocial integration.

Nevertheless, frequent appointment visits with the cleft palate team, numerous surgeries and the need for costly dental treatment can impose a heavy financial and psychological burden on the patient and their family. Surgery is performed in infancy or childhood in order to correct the orofacial cleft. More severe cases require further surgical, orthodontic and prosthodontic treatment in

adolescence and into early adulthood. For families that live in smaller communities and that have to travel great distances to visit the cleft palate team the burden is even greater.

A 1994 study based in the United States reported that the average lifetime healthcare expenditure per oral cleft patient was approximately \$100K US (26). When the oral cleft involves the alveolus and/or the palate, a considerable portion of treatment cost is attributed to dental care. Malformed teeth and hypodontia are commonly reported in these patients, with the lateral maxillary incisor being the most commonly missing tooth (27). The realignment of the dentition and the closure of edentulous sites due to missing teeth are usually achieved through surgical and orthodontic treatment. In cases where the edentulous spaces cannot be closed, prosthodontic and restorative dental treatment is required. With implants gaining favour as a standard of care for the replacement of missing teeth and as the cost of dental treatment continues to increase the financial burden on families will become even greater in the future.

Presurgical nasoalveolar molding (NAM), the most current improvement on the infant orthopaedic technique described by McNeil (39), is becoming more common practice prior to cleft palate surgery. Normally performed by an orthodontist in the first 3-4 months following birth, NAM reduces the severity of the cleft deformity, improves nasal aesthetics and often results in healthcare cost savings by reducing the need for secondary surgical procedure and alveolar bone grafts (28,29,42). Not all Canadian cleft palate clinics have embraced this treatment modality as of yet, but reports from teams that regularly use NAM when appropriate, tend to support the benefits of this form of orthopaedic therapy. The approximate cost for NAM treatment is \$3000 per patient, while the amount of coverage for orthopaedic treatment under provincial CLP dental benefit programs ranges from 0% to 100%.

### **Cleft Lip and Palate Programs in Canada**

Cleft lip and palate clinics can be found in every province with the exception of PEI. There are 21 cleft lip and palate teams operating across Canada. The teams vary in regards to their organization, function and composition depending on resources, the size of the community and population base that they serve. For example, the cleft lip and palate team working out of the Montreal Children's Hospital provides complete comprehensive care within the outpatient clinic of the hospital, whereas, the Kelowna Interior Health cleft palate team provides some outpatient care and coordinates services with health care providers in the community.

Provincial health Ministries recognise that some dental treatment is medically necessary for congenital conditions affecting the dentition. To this end, all provinces and territories have specific programs that provide for coverage of dental services for the treatment of cleft lip and palate. In some provinces the programs derive their mandates from specific legislation, whereas other provincial programs are policy-based. Although there is commonality in that all jurisdictions recognise that some dental coverage is necessary, the manner in which provinces implement programs, allocate funding for dental services, as well as select what treatment services get covered, varies extensively. For example the Manitoba Cleft Lip and Palate / Dysplasia dental benefit program provides 100% coverage for a broad range of dental services and is the payer of first resort. On the other hand, the New Brunswick Cleft Palate Program is the payer of last resort and provides 100% coverage for specific dental services, but only if the family income falls under a predetermined, and annually reviewed, threshold level. Patients and families who transfer in mid-treatment from one province to another may be surprised to find that they may no longer have the same benefits as in their province of origin.

All provincial cleft palate programs are essentially paediatric programs and include an age restriction. The cut-off age varies by province. Most CLP teams follow patients up until the cut-off age or shortly after when the initial course of treatment has been completed. Consequently, there is a great deal of treatment information available on record for patients while they are actively seeking treatment and are being followed by a multidisciplinary team; however, there is a scarcity of information as to what happens to these patients in adulthood once they are no longer eligible under the program age restriction. The extent to which assistance to adults is a concern is uncertain.

Speech, hearing, dental and breathing issues do prevail beyond childhood in patients with oral clefts. Dental problems, in particular, can continue into adulthood for a number of reasons. If the client has not received early intervention and is referred to a clinic later in life, there can be a higher incidence of problems. This is especially true of patients that are new citizens of Canada, coming from developing countries. Poor oral hygiene and inadequate dental follow-up may also result in loss of teeth and a breakdown in the results from years spent in orthodontics. In addition, the final procedures such as orthognathic surgery and subsequent lip/nasal revisions are typically planned after age 19 -limiting the follow-up that should be provided regarding speech after advancement surgery. If further follow-up is required, adult cleft patients normally receive referrals to individual team members or other specialists in a private setting.

Additionally, some clients choose to stop or delay final dental treatment because they cannot afford to pay for treatment. Another common reason to stop or delay treatment is patient burnout on account of many years of appointments, surgeries and treatments. These clients often show interest in restarting services once they have entered adulthood, or have had an opportunity to work and can afford their portion of the dental costs. At that time, they may no longer be eligible for funding according to the age restriction in the dental benefit program guidelines.

## **Methods**

After a brief review of previously collected documentation and current electronic information on CLP programs in each province and territory, telephone contact was initiated with various provincial dental and medical health authorities, private third-party claims processing administrators and CLP clinic coordinators. With the input gathered from these telephone consultations a survey questionnaire was created. It was reviewed by the Chief Dental Officer at Health Canada, then translated to French, and distributed as a form-fillable MS Word document, via email, to the same professionals that had been previously contacted by telephone. A formal letter was also sent in order to officially inform all respondents of our efforts. In total 21 surveys were sent out to cleft palate clinics and 10 surveys were sent to provincial dental/medical consultants and/or claims processing and paymaster personnel. Since many teams and programs differ in their organization and structure it would be almost impossible to design a survey instrument that can relate to all recipients equally. For this reason, some recipients were sent an abbreviated questionnaire that focussed on their area of expertise.

Responses were returned from 30 out of the 31 recipients that we contacted, resulting in a response rate of 97%. Sections of the completed review were then sent back to the provinces for final verification to ensure that the information derived from their submissions was not misinterpreted. The high number of responses has enabled us to present an accurate description of the current state of cleft palate programs across the country.

## Presentation of Findings

This Scan presents information and data that was collected through the process described above. The report is subdivided into chapters whereby each chapter provides information on CLP programs in a specific province. Due to their similarities in terms of oral cleft care support and services, the Territories are represented together. A Separate section was included to inform on benefits for eligible persons under the Non-Insured Health Benefits (NHIB) Program.

Since the scan will primarily be used as a reference guide some form of systemization was required in order to enable comparability and referencing. This was not always achievable due to differences in organization and funding structure between provinces. Thus, the following standardized format was used in representing cleft lip and palate services and dental benefit programs available in every province.

1. Province - Brief description and history of CLP facilities available in the province, and number of new and newborn patient that have been registered with the provincial clinics over the past five years.
2. Dental Benefit Programs - An account of dental benefit programs available to patients with oral clefts, and the manner in which the programs are funded and administered. The programs are described in terms of *eligibility, services covered, service provision, utilization and expenditures*.
3. Cleft Lip and Palate Team - Brief description of each CLP Team's organization and function, followed by a listing of the team members and clinic contact information.
4. Adult Patient Services– Services available for adult patients requiring medical and dental treatment related to oral clefts.
5. Speech Language Pathology (SLP) – A brief account of SLP services available to patients with oral clefts. This information was not made available for every province.
6. Medical Transportation Assistance Programs – A brief account of provincial transportation and lodging programs available to patients and patient escorts travelling long distances to receive CLP services.

## The Limits of this Scan

The ability of this scan to completely and precisely accomplish its objectives was dependent primarily upon our ability to contact key stakeholders and the ability of our survey instrument to capture pertinent information. Contacting the key stakeholders was a challenge because not all provinces have dental consultants and some programs are administered by private third-party providers. In addition, very few cleft palate clinics have information available on a website and even fewer provincial dental benefit program descriptions are readily available on the internet. In the end, we are fairly certain we contacted most, if not all, essential personnel and teams. We can also say that based on the responses, we are generally pleased with the results of the survey instrument. However, by creating questions that

were broad enough to apply to all stakeholders the ability to capture information that is unique to only one or two jurisdictions was lost. This necessitated and was rectified by several follow-up requests for additional information and clarification.

Another limitation of this review is that its accuracy is ultimately dependent on the thoroughness and exactness of the responses that were returned to us. Much of the information provided in this scan is not easily accessible or verifiable. As is usually the case with open ended questions, some respondents provided greater detail as to their organization, structure, operations and funding. This was particularly true for smaller regional CLP teams that recognized the benefit of gaining added visibility through this report. Most information that was offered was incorporated in the scan.

It is important to take note that that this scan is primarily intended as a guide to oral cleft care facilities and programs and not other craniofacial anomalies. Some CLP teams are strictly CLP teams, some are also craniofacial teams, whereas others are CLP teams that are part of a craniofacial teams and either function jointly or distinctly from the craniofacial team. We tried to make the distinction whenever it was necessary.

For similar reasons, this scan is intended to describe dental benefit programs primarily aimed at CLP. Some programs are structured such that coverage is extended to patient conditions other than oral clefts or to the general population. In these circumstances the expenditure and utilization figures solely for the treatment of oral cleft conditions is reported. If however, the claims processing office / paymaster was unable to separate the costs targeted specifically towards oral cleft care the utilization and expenditures for the entire program were reported. When the dollars spent could not be solely attributed to oral cleft treatment, a distinction was made in order to avoid confusion. Due to significant variation in program structure and benefits it is not possible to compare expenditures and utilization rates between provinces.

New patient and newborn registration data that are reported for every province are meant to represent the activity of the cleft palate clinic. It would be incorrect to add these figures for every clinic in a given province and assume that the total figures represent the number of new patients with oral clefts that are citizens of the same province. Due to regional proximity many clinics accept patients from other provinces. In addition, some patients may cease care for a period of time and then may re-register with the same or another clinic. In such cases, they may be counted as a new registered patient more than once. Since the rate of CL/P and CP remains relatively constant in Canada, one can also compare the number of births reported by Statistics Canada for every province (20), in order to roughly gauge the number of infants with oral clefts born in each province. Only Ontario and Nova Scotia register new patients into their provincial CLP dental benefit programs shortly after birth. This facilitates the accounting of clients through one central registry.

## Canada

### Non-Insured Health Benefits Program

Health Canada provides eligible First Nations people and Inuit with a specified range of medical and dental health related goods and services when they are not covered through private insurance plans or provincial/territorial health and social programs (30).

An eligible recipient must be identified as a resident of Canada and one of the following:

- A registered Indian according to the *Indian Act*;
- An Inuk recognized by one of the Inuit land Claim organizations; or
- An infant less than one year of age, whose parent is an eligible recipient.

All dentally related costs associated with the treatment of a functionally handicapping malocclusion, such as cleft palate, are covered under the Non-Insured Health Benefits (NIHB) Program. There is no age restriction. When a patient eligible for NIHB is a resident of a province, generally, the provincial program is the first payer. Thus the claim is submitted to the provincial program first, before it is submitted to the NIHB Program. However, this relationship reverses for the territories. In the Yukon, Nunavut and North-West Territories, Health Canada is the first to pay for patients eligible under NIHB. Dental treatment funding requests are reviewed by Health Canada for predetermination and patients are covered for 100% of dental rehabilitative cost in accordance with the mandate of the NIHB Program. NIHB Clients do not pay deductibles or co-payments. In addition the NIHB program covers transportation expenses for patients and escorts that must travel long distances in order to access services that are not available in their home community. Transportation benefits include the cost of travel, accommodation and meals when the clients are required to be out of the community overnight or for an extended period.

Provider guidelines for dental NIHB can be accessed at the following Health Canada website:

[http://www.hc-sc.gc.ca/fniah-spnia/pubs/nihb-ssna/\\_dent/2009-prov-four-guide/index-eng.php](http://www.hc-sc.gc.ca/fniah-spnia/pubs/nihb-ssna/_dent/2009-prov-four-guide/index-eng.php)

## British Columbia

In British Columbia there are three centres that provide health service support for patients with oral clefts. Since 1970 the Cleft Palate and Craniofacial Program at the BC Children's Hospital (BCCH), in Vancouver, has been the principal tertiary care facility for about 2,500 children with cleft lip and/or palate or craniofacial birth defects. The BCCH team also receives the majority of patients with oral clefts from the Yukon. Medical and dental coverage benefits for Yukon patients fall under their home territory. In 1968, the Cleft Lip Palate Rehabilitation Society of Vancouver Island was formed under the Societies Act and consisted of plastic surgeons and a nurse coordinator. By 1981, the program evolved into the current Cleft Lip/Palate Clinic, located at Queen Alexandra Centre for Children's Health in Victoria, which is under the administration of the Vancouver Island Health Authority. In Kelowna, a cleft palate team has been operating since 1974, providing consultation and treatment to oral cleft patients residing in the Kootenay, Okanagan, Thompson, and Cariboo Shuswap regions. The Kelowna clinic is not as large; nonetheless, it provides invaluable support for families in the BC interior that would otherwise have to travel to Vancouver. Each clinic maintains its own database registry of patients that are referred at birth or at a later stage. New and newborn patient registrations are provided in Table 1.

**Table 1. British Columbia Cleft Lip and Palate Clinic Patient Registration 2005-2009**

<b>YEAR</b>	<b>BC Children's Patients registered (Newborn Patients)</b>	<b>Queen Alexandra Centre Patients Registered (Newborn Patients)</b>	<b>Interior Health Patients Registered (Newborn Patients)</b>
2009 (as of June)	N/A (27)	~ 12 (3)	1 (0)
2008	N/A (69)	~ 25 (11)	4 (1)
2007	N/A (64)	~ 25 (9)	6 (4)
2006	N/A (62)	~ 25 (8)	4 (1)
2005	N/A (78)	~ 25 (8)	3 (0)

### British Columbia Cleft Lip and Palate Dental Benefit Programs

In British Columbia, patients with oral clefts can receive dental treatment benefits through two programs funded by the Ministry of Health Services. The first program, identified as the Orthodontic Program for Children with Cleft Lip and Palate and Syndromic Craniofacial Anomalies, administered through the provincial Medical Services Plan, has been in place for over 35 years. The purpose of the program is to provide financial assistance for orthodontic care to the families of children born with cleft lip and or palate or a syndromic craniofacial anomaly. Under the program, expenses for newborn pre surgical orthopaedic, speech bulb and palatal obturator appliances are also covered. The cost of eligible dental services and devices is covered at 100% and the program is the payer of first resort.

In the late 1990's the BC government initiated funding of a second program aimed to provide financial assistance for the prosthetic treatment that at times could be required following orthodontic treatment to close a gap from a congenitally missing tooth in the line of a cleft. This program, termed Cleft Lip and Palate Prosthetic Program, is administered through the BC Dental Association through a grant provided by the Ministry of Health. The current conditions of the grant are for \$200,000 over



three years, April 1, 2007 to March 31, 2010. Private insurance, if in place, is expected to be the first to pay, prior to the program.

## 1. Orthodontic Program for Children with Cleft Lip and Palate & Syndromic Craniofacial Anomalies

**Eligibility:** This program is available to all children, not older than 19 years of age, who have a confirmed medical diagnosis of Cleft lip and/or palate or syndromic craniofacial anomaly requiring both orthodontic treatment and surgery of the facial skeletal structure.

**Services:** The Program covers 100% of orthodontic treatment and is the payer of first resort. Items such as obturators, feeding appliances, nasoalveolar appliances and nasal stents are also covered.

**Service Provision:** Providers must be certified orthodontists registered with the College of Dental Surgeons of BC. In situations where the nearest location for treatment services is outside the Province but in Canada, the provider can be a specialist entitled to practice dental surgery in the region where the service is rendered.

**Utilization and Expenditures:** Total expenditures under the program and expenditures solely for Cleft Lip and/or Palate patients are provided in Tables 2 and 3. Once treatment is approved fees are paid quarterly; therefore, annual costs represent on-going charges and completed cases. Since the number of children born with orofacial clefts remains fairly constant, rising annual costs may be due to negotiated fee increases rather than more demand for services.

**Table 2. Total expenditures under the program (includes cleft lip and palate and other craniofacial anomalies)**

YEAR	TOTAL PROGRAM COST
2008	\$1,048,100
2007	\$931,514
2006	\$872,650

**Table 3. Utilization and expenditures solely for Cleft Lip and/or Palate patients under the program**

YEAR	NUMBER OF PATIENTS PROVIDED WITH BENEFITS (new cases for the year)	TOTAL COST for Cleft Lip and/or Palate Patients
2008	295 (90 new)	\$870,589.99
2007	241 (54 new)	\$720,144.83
2006	280 (78new)	\$855,949.44

## 2. Cleft Palate and Prosthetic Program

**Eligibility:** Patients 25 years or younger, who were born with a cleft lip/palate and require the replacement of congenitally missing teeth, and have completed treatment through the Cleft lip and Palate and Syndromic Craniofacial Anomalies Program.

**Services:** Benefits covered under the program include prosthetic treatment such as crowns, bridges, implants and dentures. The Program covers 100% of treatment cost and is the payer of last resort.

**Service Provision:** Treatment can be carried out by a referring dentist, dental specialist or a combination of both. A BCDA expert screening committee, made up of three unpaid volunteer dentists, reviews treatment plans and can make treatment suggestions when appropriate to the referring dentist. Payment is made after notification by the referring dentist that treatment has been completed.

**Utilization and Expenditures:** Total expenditures and number of cases completed under the program are provided in Table 4.

**Table 4. Utilization and expenditures for Cleft palate and Prosthetic Program**

YEAR	NUMBER OF COMPLETED CASES	TOTAL COST
2008	9	\$20,750.12
2007	12	\$43,422.04
2006	16	\$50,136.21

## **British Columbia Cleft Lip and Palate Clinics**

### **1. BC Children's Hospital Cleft Palate / Craniofacial Clinic**

The Cleft Palate Clinic is held on a weekly basis, almost every Tuesday morning. Approximately 450 patients are seen annually. In addition one craniofacial clinic day and one jaw clinic day are conducted every month. Team participants include a paediatrician, plastic surgeon, orthodontist, otolaryngologist, audiologist, social worker, nurse clinician and a speech-language pathologist (SLP). A maxillofacial surgeon is present for Jaw Clinic days. Ten patients are usually seen during a Cleft Palate Clinic morning, whereas five to six patients are seen during Craniofacial and Jaw Clinics. The entire team meets four times per year to discuss current and outstanding concerns.

The multidisciplinary team provides on-going assessment, treatment planning, case management and coordination, follow-up, and treatment intervention services. The team also provides antenatal counselling sessions for families, with the nurse/coordinator. Clients are referred from Fetal Diagnostics at BC Women's Hospital, an adjacent hospital within the same health authority. Newborns are referred by family doctor or pediatrician. All other patients are referred by a physician. Patients with oral clefts are followed by the entire team until they are approximately 18 years old. They are then followed by some team members in their private offices, as necessary.

A full summary of services and patient educational materials are available on the hospital website at: <http://www.bcchildrens.ca/Services/SurgeryAndSurgSuites/CleftPalateCraniofacialSurgery/default.htm>

<b>BC Children's Hospital Cleft Palate / Craniofacial Team</b>	
<b>Team leader</b>	<b>Sandra Robertson (Nurse Clinician)</b>
Geneticist	
Paediatrician	Dr. Christine Loock, Dr Jenny Druker
Otolaryngologist	Dr. Jeff Ludemann, Dr. fred Kozak, Dr. Paul Moxham
Paediatric Dentist	Dr. Doug Johnston
Prosthodontist	Dr. Leo Fung
Oral Surgeon	Dr. Mark Reichman
Plastic Surgeon	Dr. Kevin Bush, Dr Doug Courtemanche, Dr. Jugpal Arneja, Dr. Cindy Verchere
Orthodontist	Dr. Sam Chiang, Dr. Paul Helpard, Dr. Angie Loo, Dr. Paul Pocock
Dentist	
Speech pathologist	Sheryl Palm, Jennifer Fraser
Audiologist	Kathy Barker
Nurse Coordinator	Sandra Robertson
Social Worker	Kelly Allison
Psychologist	
Other	Sharon Vance (program secretary), Reymie Krefting (program secretary)
Administrator	

**Clinic Contact Information:**

Address: British Columbia Children's hospital  
4480 Oak Street  
Vancouver, BC, V6H 3J4

Tel: 604-875-3146  
Fax: 604-875-2473  
Email: [srobertson@cw.bc.ca](mailto:srobertson@cw.bc.ca)

## **2. Queen Alexandra Centre for Children's Health Cleft Lip and Palate Clinic**

The Victoria Cleft Lip/Palate team meets 11 times per year (typically the 4th Tuesday of the month), in the afternoon from 1:30- 6:30 pm. On average 6 -7 children are seen individually by the following team members during their clinic visit: paediatrician, plastic surgeon, otolaryngologist, paediatric dentist and orthodontist, SLP, audiologist, and clinic nurse. The appointment times are staggered to minimize wait time for the families. After examining the children, the team will consult to discuss recommendations and determine a treatment plan for all of the children at the clinic. Additional time is available for chart reviews of other children not scheduled at the clinic and to discuss topics related to professional development (conferences attended, journal articles). Children with complex craniofacial conditions are referred to BCCH. In addition to organizing the clinics and providing speech therapy follow-up for local preschool children in the Victoria area, the Clinic Coordinator maintains contact with families and service providers in the community between clinic visits, and maintains files with documentation. The parents give the clinic their consent to send out full team reports with dictation from all team members to service providers in the community. The parents also receive copies of the clinic reports

The Cleft Palate Clinic program provides services to children from birth to age 19. Referrals are accepted for children with any cleft related issue, if the family resides on Vancouver Island or the Gulf Islands. Some of the children are referred from birth, and others are referred at an older age when there is a concern regarding a possible submucous cleft palate and hypernasal speech. Referrals and transfers are also received from other cleft palate programs in Canada. Some of the children have recently been adopted from other countries and are new citizens.

Newborn referrals typically come from the primary care physician or paediatrician. When a cleft lip is identified prenatally, the mother's physician will contact the Clinic Coordinator or Medical Coordinator. At the parents' request, a prenatal consultation is available with the clinic coordinator or nurse in order to provide further information and support. If the baby is born in Victoria, a hospital visit is offered by the Clinic Coordinator to show pictures, to register the child with the clinic and to assist with feeding. If the newborn referral is from out of town, a telephone call is made to the referring physician and parent to share information, register the child and offer a clinic appointment date. Referrals for older children typically come from otolaryngologists, Speech Pathologists or other Cleft Palate Clinic coordinators. As soon as a referral is received, the parent is contacted.

Most of the team members have been committed to cleft palate care for a long period of time providing the benefit of experience and good interdisciplinary discussion and ongoing learning. The recent inclusion of both an orthodontist as well as a pediatric dental specialist has enhanced treatment planning management. Furthermore, improved access to diagnostic procedures like nasopharyngoscopy and digital videofluoroscopy for speech assessment, and ototacoustic emission screening for hearing have greatly improved treatment outcomes by optimizing a child's speech and hearing prior to school entry.

<b>Queen Alexandra Centre for Children's Health Cleft Lip and Palate Team</b>	
<b>Team leader</b>	<b>Dr. J. Popkin (Medical Coordinator/Pediatrician)</b>
Geneticist	On Referral
Paediatrician	Dr. J. Popkin
Otolaryngologist	Dr. K. Clarke
Paediatric Dentist	Dr. L. Magne
Prosthodontist	
Oral Surgeon	
Plastic Surgeon	Dr. D. Naysmith, Dr. J. Gray
Orthodontist	Dr. H. Lamont
Dentist	
Speech pathologist	Maureen O'Brien
Audiologist	
Nurse Clinician	Margaret Coxon
Social Worker	
Psychologist	
Other	Audrey Gibson (Program Manager), Terina Hemeon (Clinic Assistant)
Clinic Coordinator	Maureen O'Brien (SLP)

**Clinic Contact Information:**

Address: Queen Alexandra Centre for Children's Health  
2400 Arbutus Rd.  
Victoria, BC, V8N 1V7

Tel: 250-519-5390 (local 36329)

Fax: 250-519-6907

Email: [maureen.m.obrien@viha.ca](mailto:maureen.m.obrien@viha.ca)

### **3. Interior Health Cleft Lip and Palate Clinic**

The Interior Health Cleft Lip and Palate clinic was started in Kelowna, in 1974, by community health providers who realized that expertise was available locally and families did not have to travel all the way to Vancouver, a seven hour drive at that time. This was an invaluable and welcomed necessity for many families from throughout the BC interior who found it difficult and costly to commute to the Cleft Palate Clinic in Vancouver in order to receive surgery, treatment and maintain regular follow-up. This commitment to serving the community continues today through the collaboration between the Cleft Palate Team and the local health service providers.

The team clinics, consisting of otolaryngologist, plastic surgeon, paediatrician, SLP, audiologist, orthodontist and dental hygienist, are held four times per year (2 mornings in the spring; 2 Mornings in the fall). Throughout the remainder of the year the Team will stay in contact through correspondence. The team clinics are considered solely as assessment/advisory clinics, intended for coordinating patient evaluation and helping families access service providers in their local community. Other than the services provided by the team members, additional referrals may be made for services provided by paediatric dentists, oral surgeons, public health nurses, social workers and mental health professionals. Typically, six families will be seen during a team clinic. In between clinics, the team leader handles inquiries and acts as a resource for immediate needs. Local community assessment/treatment is ongoing and separate from the Team Clinics.

The team receives approximately four new patients annually. These patients may be newborns, children referred by health care providers or new patients that have moved to the region. At least one team member, normally the plastic surgeon, will visit the parents in the Hospital as soon as possible after the baby is born. If the child is older at the date of referral, the family will be invited to the next Clinic. Once a family is seen, the Team recommends a call back time based on the needs of the family and age of the child. This could be as soon as 6 months, or as far in the future as 4 years. The average recommendation is for 2-3 years and a family is followed by the Team until their child reaches about 18 years of age.

<b>Interior Health Cleft Lip and Palate Team</b>	
<b>Team leader</b>	<b>Lynda Martyn, SLP</b>
Geneticist	Access through Outreach Clinic in Vancouver
Paediatrician	Dr. Mark Duncan
Otolaryngologist	Dr. Ben Achtem, Dr. Tim Kramer
Paediatric Dentist	
Prosthodontist	
Oral Surgeon	Access through Dr Richard Bell (Kelowna)
Plastic Surgeon	Dr. Stan Valnicek, Dr Scott Williamson
Orthodontist	Dr. Cliff Moore, Dr Iain Allan
Dentist	
Speech pathologist	Lynda Martyn
Audiologist	Permanent position at Kelowna Health Centre currently vacant
Nurse Coordinator	
Social Worker	On referral
Psychologist	On referral
Other	Shawna Gibb (Dental Hygienist), Sharon Melanson (Dental Hygienist)
Administrator	

**Clinic Contact Information:**

Address: Interior Health Cleft Lip/Palate Clinic  
Kelowna Health Centre  
1340 Ellis Street  
Kelowna, BC, V1Y 9N1

Tel: 250-868-7757  
Fax: 250-868-7809 (Attn Lynda Martyn)  
Email: [lynda.vivian@interiorhealth.ca](mailto:lynda.vivian@interiorhealth.ca)



## **Adult Dental Treatment**

Patients are followed routinely up to the age of 18. Orthodontic treatment may be recommended after 19 years of age due to factors affected by skeletal growth; nevertheless, in order to receive authorization under the MSP program, the treatment plan must be submitted prior to the cut-off age of 19. Following the completion of orthodontic and prosthodontic treatment, dental benefits are discontinued and long term follow up care and maintenance becomes the patient's responsibility. The only exception is the renewal and relining of palatal obturators which are covered throughout adulthood.

## **Speech-Language Pathology**

Speech-Language Pathology consultative services for children born with cleft lip and/or palate are funded by the Ministry of Health or the Ministry of Child and Family Development. From birth to kindergarten entry is through the community Public Health Centres or Child Development Associations. Once the child has reached school age, SLP services are provided through the school district by the Ministry of Education. Adults can receive SLP services through BC hospitals. Private speech therapy is available throughout the province at any age.

## **Travel**

The Ministry of Health funds two programs to assist eligible patients and escorts with the cost of travel required in order to obtain non-emergency medical care that is unavailable in their home community. The Travel Assistance Program relies on the participation of transportation partners and provides financial assistance for the cost of ferries and flights. The Health Connections Program is implemented by the four Health authorities in BC, and provides regional travel options for rural residents. Both programs require a physician's referral. These two programs could be accessed when travel is required for in-hospital surgical correction of the lip and palate and the initial diagnostic services but not for follow-up appointments such as orthodontic care. The programs do not pay for lodging, but the cleft palate clinic team can provide recommendations for discounted accommodations.

## Alberta

There are two clinics in Alberta, operating under Alberta Health Services, which care for patients with oral clefts. In Edmonton, the Stollery Children’s Hospital has been assessing and treating patients since 1954, while the clinic at the Alberta Children’s Hospital, in Calgary, has been operating since 1970. The two hospitals employ a slightly different team set-up. The Stollery has a Cleft Lip and Palate team that focuses on oral clefts, and a separate and distinct craniofacial team that treats syndromic conditions, such as Pierre Robins, Apert, and Crouzon. On the other hand, the Alberta Children’s Hospital maintains an all encompassing Cleft Palate/Maxillofacial team that treats all patients with oral clefts and craniofacial anomalies.

Parents are often referred to the clinics after antenatal diagnosis on ultrasound. Newborn patients are referred by the delivery hospital at birth. New residents to the province are also received through a referral or by contacting one of the clinics. The Stollery and the Alberta Children’s Hospital also receive patients from the territories and neighbouring border towns in British Columbia and Saskatchewan. New and newborn patient registrations are provided in Table 5.

**Table 5. Alberta Cleft Lip and Palate Clinic Registrations 2005-2009**

YEAR	Stollery Children’s Edmonton Patients Registered (Newborn Patients)	Alberta Children’s Calgary Patients Registered (Newborn Patients)
2009 (as of June)	50 (21)	11 (11)
2008	86 (54)	43 (35)
2007	75 (50)	59 (42)
2006	79 (32)	N/A (N/A)
2005	105 (43)	N/A (N/A)

Public dental financing for patients with oral clefts is provided through the Cleft Palate Dental Indemnity Program. Patients with craniofacial anomalies that do not have a cleft of the hard palate may be eligible to receive coverage through the Oral Maxillofacial Devices and Services (OMDS) Program. The OMDS program, which will not be addressed in this scan, provides coverage for some “high cost” dental treatments that are required in conjunction with an insured oral surgical procedure under the Alberta Health Care Insurance Plan.

## The Cleft Palate Dental Indemnity Program

Alberta's Cleft Palate Dental Indemnity Program has been providing dental benefits to patients with oral clefts since 1974, and is recognized as the first publicly financed cleft palate dental benefit program in Canada. The program is funded through a grant from the Department of Alberta Health and Wellness. In June 2008, Alberta Health and Wellness transferred the administration of the program to Alberta Health Services. The terms of the current grant are scheduled to end in March 2010 with plans to implement a further 3 year grant to 2013.

The program partially subsidizes dental treatment solely for patients with a cleft of the hard palate and/or alveolus. A payment schedule is utilized that covers a portion or all of the fees that Alberta dentists charge their patients. The Schedule of Benefits is revised annually in order to maintain benefits in alignment with the industry standards. The Program is the payer of last resort and supplements third party coverage up to the Program Schedule of Benefits maximum price. Patients are responsible for payment of the difference between the dentist's fee, private insurance coverage if applicable, and the Program Schedule of Benefits fee.

Claims are submitted by general dentists and dental specialists. A Program dental consultant/adjudicator, usually an oral surgeon or orthodontist hired under contract by Alberta Health Services, assesses all treatment plans in accordance with program guidelines and fees. Once a treatment plan is approved by the consultant, funding may be authorized by Alberta Health Services.

**Eligibility:** This program is available to all Alberta residents, 24 years of age or younger, that have a complete or incomplete cleft affecting the alveolus (where there is a bony defect or congenitally missing tooth) or of the hard palate with orthodontic implications, as determined by a program dental consultant. Patients over the age of 25 may also be eligible following an exceptional case review process.

**Services:** A range of diagnostic, preventive and treatment services (restorative, endodontic, periodontic, prosthodontic, orthodontic, oral surgery, implants) in the amount described in a schedule of dental procedures and fees. Some dental treatment coverage under the Program is restricted to the two teeth on either side of the cleft unless otherwise stated in the guidelines. Nasoalveolar moulding appliance cost is covered at 100% cost.

**Service Provision:** Dentists, dental hygienists and dental specialty providers.

**Utilization and Expenditures:** Prior to 2008, patient claims were processed by a contract company, whose system did not provide reporting on specific cost breakdowns. Dental benefits paid out to cleft lip and palate patients are provided in Table 6.

**Table 6. Alberta Cleft Palate Dental Indemnity Program Expenditures and Utilization**

YEAR	NUMBER OF CLAIMS	TOTAL COST ORTHODONTICS	TOTAL COST PROSTHODONTICS	TOTAL Expenditures
2008	355	\$191,481	\$52,974	\$511,543
2007	534	N/A	N/A	\$567,652
2006	N/A	N/A	N/A	\$490,687

## Alberta Cleft Lip and Palate Clinics

### 1. Stollery Children's Hospital Cleft Palate Clinic

There are approximately 96 half clinic days involving the partial team (SLP, audiologist, social worker, otolaryngologist) every year. Clinics are held Monday and Wednesday mornings, and normally 4 or 5 patients are seen. There are also 20 full team clinics (partial team plus paediatrician, plastic surgeon, orthodontist, oral surgeon) in a year, which take place on Mondays. Between 20 and 30 patients are seen during a full team clinic day.

<b>Stollery Children's Hospital Cleft Palate Team</b>	
<b>Team leader</b>	<b>Dr. Gordon Wilkes, Plastic Surgeon</b>
Geneticist	On referral
Paediatrician	Dr. I. Buka
Otolaryngologist	Dr. E. Eksteen
Paediatric dentist	From community
Prosthodontist	Dr.Keith Compton
Oral Surgeon	Dr. K. Lung
Plastic Surgeon	Dr. G. Wilkes, Dr. J. Olson
Orthodontist	Dr. E. Diduch
Dentist	
Speech pathologist	Sharon Hundert
Audiologist	Julie Kremer, Steven Clements, Charlene Thompson, Margo McNiven
Nurse Coordinator	
Social Worker	Jennifer Ellis
Psychologist	On referral
Other	
Administrator	Shelly Leeb

#### Clinic Contact Information:

Address: Stollery Children's Hospital  
8440 112 Street  
Edmonton, AB, T6G 2B7

Tel: 780-407-6994  
Fax: 780-407-6586  
Email: [shelly.lee@albertahealthservices.ca](mailto:shelly.lee@albertahealthservices.ca)

## 2. Alberta Children’s Hospital Cleft Palate / Maxillofacial Clinic

A full day oral cleft clinic is held every Wednesday. The morning clinic sees children up until the age of 6 years and is attended by the plastic surgeon, nurse, paediatrician, otolaryngologist, paediatric dentist, audiologist and SLP. The afternoon clinic sees children six years of age and greater and is attended by the plastic surgeon, nurse, otolaryngologist, oral surgeon and orthodontist. The clinic will see approximately 20 children during a clinic day. There is a post surgical conference held after the morning and afternoon clinics for further discussion and treatment planning.

<b>Alberta Children’s Hospital Cleft Palate / Craniofacial Team</b>	
<b>Team leader</b>	<b>Dr. McPhalen, Plastic Surgeon</b>
Geneticist	On referral
Paediatrician	Dr. Kendrick, Dr. Walker
Otolaryngologist	Dr. Brookes, Dr. Drummond, Dr. Lange
Paediatric Dentist	Dr. Cholette, Dr. Hulland, Dr. Bell
Prosthodontist	
Oral Surgeon	Dr. Vincelli
Plastic Surgeon	Dr. Harop, Dr. McPhalen, Dr. Dilay, Dr. Fraulin
Orthodontist	Dr. Mehra, Dr. Bindman
Dentist	
Speech pathologist	Cindy Humphries, Allison MacDonald
Audiologist	Sylvia Lambert
Nurse Coordinator	Kimberley Johnston, Debbie McIntyre
Social Worker	Ruanna Jones
Psychologist	On referral
Other	
Administrator	Tracey Nelson

### Clinic Contact Information:

Address: Alberta Children’s Hospital  
2888 Shaganappi trail NW  
Calgary, AB, T3B 6A8

Tel: 403-955-7694

Fax: 403-955-7799

Email: [Kimberley.johnston@calgaryhealthregion.ca](mailto:Kimberley.johnston@calgaryhealthregion.ca)

## **The Adult Patient**

Patients, 24 years or younger, are eligible for benefits under the Program regardless of the stage of treatment they are in. These patients will have their pre authorization claims, treatment plans and radiographs forwarded directly to the cleft palate clinic for review. Patients over the age of 25 may also be eligible for benefits under the program; however, their treatment plan must first undergo an “exceptional case” review process. A consultant reviews each “exceptional case” individually and drafts a briefing paper describing the circumstances. The Patient Care Manager and Cleft Palate Dental Indemnity Analyst in conjunction with the dental consultant decide whether the patient will be entitled to Program benefits.

## **Speech Language Pathology**

All children affected by a cleft lip and/or a cleft palate are assessed for speech at 12 to 15 months of age; usually three months following cleft palate repair. Speech therapy will either be provided by the team in the outpatient clinic or in the local community, at no cost to the family. There is no age restriction for therapy.

## Saskatchewan

Two clinics in Saskatchewan provide multidisciplinary services to patients with oral clefts. Saskatchewan Health coordinates the provision of health services through the province's regional health authorities. In Regina, the Cleft Palate Clinic at the Wascana Rehabilitation Centre has been operating since 1979. The Regina Qu'Appelle Health Region supports the clinic with its own health care providers and hired medical and dental consultants from the local community. The other Cleft Lip and Palate Clinic is located at the Royal University Hospital, in Saskatoon, and is supported by the Saskatoon Health Region. There is no provincial registry for cleft lip and palate patients in the province, patients are solely registered at the respective clinics. The number of registrations of new and newborn patients with oral clefts, are provided in Table 7.

**Table 7. Clinic Registrations 2005-2009**

YEAR	Royal University Hospital Cleft Lip and Palate Clinic New Patients registered (Newborns)	Wascana Cleft Lip and Palate Clinic New Patients registered (Newborns)
2009 (as of June)	N/A (N/A)	10 (2)
2008	N/A (N/A)	16 (11)
2007	N/A (N/A)	16 (10)
2006	N/A (N/A)	13 (6)
2005	N/A (N/A)	14 (4)

### **Saskatchewan Health Medical Services Plan - Dental Benefits for Patients with Cleft Palate**

The Saskatchewan Health Medical Services Plan (MSP) insures dental services for patients with oral clefts in accordance with the MSP payment schedule for dentists and dental specialists. Fees for insured dental services under the MSP payment schedule are negotiated with the Saskatchewan Dental Association on a regular basis. MSP fees are lower compared to the recommended fees published in the Saskatchewan Dental Association fee guide. Dentists providing treatment are not permitted to bill the patient for the difference between MSP fees and the professional fee guides. As such, patients receive 100% coverage for insured dental services. The MSP is the payer of last resort.

Orthodontic services necessary and consequential to a cleft of the hard palate are insured services covered under the MSP payment schedule. Other congenital craniofacial anomalies can also be considered for coverage when orthodontic services are deemed necessary and consequential to the diagnosed congenital abnormalities. Orthodontists must submit a full treatment plan and photographs, and list the codes they wish to bill under the payment schedule. Saskatchewan health employs a contracted dental consultant who reviews applications to determine eligibility.

At the present time, restorative and prosthodontic treatment (crown and bridges, partial dentures, osseointegrated implants) to replace missing or deformed teeth due to cleft palate or other congenital anomalies are not insured services under MSP. In addition, nasoalveolar moulding appliances and treatment are not covered under MSP; however, coverage for this treatment modality is currently being reviewed. General dentistry is not covered under the Plan.

## MSP – Dental Coverage for Patients with Cleft Palate

**Eligibility:** A beneficiary must be a resident of Saskatchewan, under the age of 22, and referred by a physician, a dentist or a cleft palate clinic for orthodontic services necessary and consequential to a cleft of the hard palate.

**Services:** Obturators, feeding appliances and orthodontic diagnostic and treatment services are covered under the MSP.

**Service Provision:** Dentists and dental specialists can provide services, as designated by the MSP Schedule.

**Utilization and Expenditures:** Utilization and Expenditures for dental benefits covered under the MSP, in recent years, are represented in table 8.

**Table 8. Total Expenditures for Cleft Palate under the MSP Program**

Fiscal YEAR (01 Apr-31 Mar)	NUMBER OF Discrete Patients	Number of Services Rendered	TOTAL Expenditures
2008 - 09	126	439	\$79,235
2007 - 08	128	564	\$91,668
2006 - 07	134	565	\$78,575



## Saskatchewan Cleft Lip and Palate Clinics

### 1. Wascana Rehabilitation Centre Cleft Lip and Palate Clinic

Cleft palate clinic days are held every second month at the Wascana Rehabilitation Centre. The team sees between eight and ten patients during a half-day. Team members include the SLP, audiologist, nurse clinician, social worker, dietician and photographer employed by the Qu'appelle region, and a paediatric dentist, plastic surgeon, orthodontist and otolaryngologist hired from the community and paid as consultants. All members examine the patients individually and provide recommendations that are incorporated into a care plan. The entire clinical team holds an administrative meeting once per year.

Newborns are referred from acute care to the cleft palate clinic nurse coordinator. Members of the team will meet the family in acute care and provide information about the Cleft Lip and Palate Clinic. Referrals of older patients come from physicians to the clinic coordinator. New assessments will be booked at the next available clinic time. Clinic follow-up frequency is based on patient need. Ongoing appointments are made based on the care plan. The clinic follows children up to the age of 18 years, at which time they are discharged from the register.

<b>Wascana Rehabilitation Centre Cleft Lip and Palate Clinic</b>	
<b>Team leader</b>	<b>Dr. P.S. Chang, Plastic Surgeon</b>
Paediatrician	
Otolaryngologist	Dr. L. Pillay
Paediatric Dentist	Dr. D. Avram
Prosthodontist	
Oral Surgeon	
Plastic Surgeon	Dr. P.S. Chang
Orthodontist	Dr. M. Ziglo
Speech pathologist	Carolyn McKinnon, Susan Lolacher, Donna Jackson
Audiologist	Coreen Richardson
Nurse Coordinator	Jill Scheske
Social Worker	Sandra Palandri
Other	Becky Poole (Dietician), Scott Wilson (Biomedical Media Technician)
Administrator	Lorie Kinneberg (Children's Program Manager)

#### Clinic Contact Information:

Address: Wascana Rehabilitation Centre  
2180 – 23<sup>rd</sup> Ave.  
Regina, Saskatchewan, S4S 0A5  
Tel: 306-766-5546  
Fax: 306-766-5189  
Email: [jill.scheske@rqhealth.ca](mailto:jill.scheske@rqhealth.ca)

## **2. Royal University Hospital Cleft lip and Palate Clinic**

The Cleft lip and Palate Team from the Royal University Hospital, in Saskatoon, did not respond to the survey questionnaire. For this reason a description of clinic organization and function is not reported. The clinic contact information for this centre is provided.

### **Clinic Contact Information:**

Address: Royal University Hospital Cleft lip and Palate Clinic  
103 Hospital Drive,  
Saskatoon, SK S7N 0W8

Tel: 306-966-2922

Fax:

Email: [kathy.nelson@saskatoonhealthregion.ca](mailto:kathy.nelson@saskatoonhealthregion.ca)

### **The Adult Patient**

Normally, a patient must commence treatment no later than 21 yrs of age in order to be eligible for dental benefits. Under special conditions a patient older than the age of 21 may be accepted for dental treatment coverage under the MSP. The province's dental consultant will review these exceptional cases, on an individual basis, and make a recommendation to MSP whether to approve or deny coverage.

## Manitoba

In Manitoba, the cleft lip and palate clinic has been operating at the Children's Hospital of Winnipeg since 1980. Manitoba Health funds the program through the Winnipeg Regional Health Authority. The program is currently undergoing a name change and will soon be referred to as the Manitoba Centre for Craniofacial Difference (MCCD). The name change is intended to lend recognition to the fact that the oral cleft team is just one subgroup of a larger craniofacial team capable of handling all types of craniofacial difference, and not just cleft lip and palate.

New patients are registered into the program after a consultation with the dental clinic director. Patients are referred to the clinic as newborn patients, new citizens or provincial transfers after they have obtained a Manitoba Health Services Commission (MHCS) number. Due to the lack of cleft lip and palate team services available in the region, clients from Ontario, Saskatchewan and Nunavut are also registered at the Children's Hospital in order to receive multidisciplinary care. For out of province patients, medical and dental coverage benefits will fall under their home province or territory. For example, Ontario patients are also registered with the Bloorview Clinic in order to receive their benefits in accordance with the Ontario Cleft Lip and Palate/Craniofacial Dental Program. The number of registrations of new and newborn patients with oral clefts, are provided in Table 9.

**Table 9. Children's Hospital of Winnipeg Cleft Lip and Palate Clinic Registration 2005-2009**

YEAR	Patients Registered	Newborn Patients
2009 (as of June)	22	20
2008	38	34
2007	36	33
2006	34	34
2005	49	40

## Manitoba Cleft Lip and Palate / Dysplasia Dental Benefit Program

In 1980, Manitoba Health assumed the responsibility for the dental treatment of Manitoba residents born with a cleft lip and/or palate. This came about at a time when Manitoba, as well as other western provinces, were increasing spending and expanding dental programs for children. However, although public funding for children's dental programs has been greatly scaled-back since the mid-1980's, the province has always recognized that children born with congenital conditions affecting the dentition should be afforded more rather than less. In 1995, at the government's request, the program was extended to include children with significant oral facial dysplasia and other anomalies that affect the dentition. As the primary insurer, the program covers 100% of the cost of almost all dental treatment (certain prosthodontic procedures may have limited funding). A commitment was made to be the payer of first resort because dental care for children with oral clefts can quickly exhaust family benefits under private insurance plans, which can lead to less funding available to other family members and/or children with cleft palate not obtaining required treatment. Therefore, being the payer of first resort ensures that patients are getting all the treatment that is required and also serves as a source of

information for tracking completed dental services. This is because all dental claims must go through the Children’s Hospital clinic claims manager prior to being forwarded to Manitoba Health. In 2007, coverage was broadened to include dental implants and prolong eligibility past the age of 18, or until the treatment plan is deemed completed by the Cleft Lip and palate/Craniofacial (CLP/C)Team. Due to the financial investment that is made on the care for patients with oral clefts, it is a requirement under the program that patients undergo annual dental check-up examinations and maintain an acceptable level of oral hygiene in order to retain enrolment.

**Eligibility:** To be eligible for benefits, a patient must be a Manitoba resident, under the age of 18, registered with the cleft palate team and have a valid MHSC number. Manitoba residents over the age of 18 years may be considered for benefits on review by the CLP/C Team. Furthermore, the team makes it a requirement that patients undergo annual dental check-up examinations and maintain an acceptable level of oral hygiene in order to retain enrolment under the plan.

**Services:** As a payer of first resort the plan covers 100% of the cost of all dental treatment. This includes annual dental examinations, preventive, restorative, endodontic, periodontic, orthodontic and prosthodontic treatment.

**Service Provision:** Under the plan any dentist may provide treatment, however orthodontic, periodontic and prosthodontic treatment must be provided by a dental specialist. Preapproval is required for treatment over \$500.00. Dental implants require further preapproval through the Manitoba Health Implant Committee.

**Utilization and Expenditures:** There are currently 716 active patients enrolled under the program. Dental benefits paid out under the Cleft Lip and Palate/Dysplasia Program are provided in Table 10.

**Table 10. Manitoba Cleft Lip and Palate / Dysplasia Dental Benefit Program Expenditures and utilization**

YEAR	Number of Patients that accessed benefits	ORTHODONTIC EXPENDITURES (NUMBER OF CLAIMS)	DENTAL EXPENDITURES (NUMBER OF CLAIMS)	TOTAL PROGRAM EXPENDITURES (NUMBER OF CLAIMS)
2008	716	\$162,334 (280)	\$249,812 (1241)	\$412,146 (1521)
2007	633	\$132,009 (175)	\$197,879 (1106)	\$329,888 (1281)
2006	624	\$144,917 (229)	\$155,752 (1063)	\$300,709 (1292)

## **Children's Hospital of Winnipeg Cleft Lip and Palate/Craniofacial Clinic**

After receiving referrals from the Fetal Assessment Unit or Geneticist, the Nurse Clinician will meet with families prenatally to answer questions and offer program information and support. All newborns will attend an appointment with the Nurse Clinician within the first month following birth in order to address feeding concerns and to be assessed for pre-surgical treatment. Initial consultation with the Plastic Surgeon and paediatric dentist will occur by 2 months of age and lip repair surgery is planned for 3-4 months of age. The Otolaryngologist coordinates any required surgical intervention with lip & palate repair surgery when at all possible. Speech and Genetics will see families within the first 6 months of life. Palate repairs take place at approximately 9-12 months of age. All team players are responsible for their own guidelines and protocols for follow up and ongoing care. Appointments for treatment and services are coordinated, by the Nurse Clinician, so as to minimize unnecessary travel and disruption to the families.

The team clinic is held every other Thursday, with the exception of July and August, resulting in approximately twenty clinic days per year. Patients are generally seen in this forum at age 5 years, 12 years, 15 years and at craniofacial maturity (18-21 years of age). Ten patients are usually seen by seven team specialists, on a clinic day.

10h00 - Appointments begin with Audiograms and follow-up with ENT, as required.

11h00 - Everyone reports to the dental clinic for radiographs and an examination with the Paediatric Dentist.

12h00 - Families are encouraged to have lunch.

13h00 - The patients and families will meet with the Speech-Language Pathologist for assessment, the Social Worker for an interview and the Plastic Surgeon for review. Plans for treatment, intervention or surgery can be discussed during this time, and surgical consent is obtained.

14h30 - The Oral Surgeon, Orthodontist and Prosthodontist review each patient together with the paediatric dentist. Once patients have seen each team member they are dismissed for the day.

16h00 - The team members usually meet in order to discuss all the patients that were seen that day.

Multidisciplinary discussion and treatment planning take place in the absence of the patient and family. In the week following the clinic appointment, the Nurse Clinician will send a letter to the family and all involved team members, outlining the visit, the discussion that took place and any plans for the future.

<b>Children's Hospital of Winnipeg Cleft Lip and Palate/Craniofacial Team</b>	
<b>Team leader</b>	<b>Dr. L. Ross, plastic surgeon and director of the MCCD</b>
Geneticist	Dr. Chudley
Paediatrician	
Otolaryngologist	Dr. D. Leitao
Paediatric dentist	Dr. H. Cross (Director of the Dental Clinic)
Prosthodontist	Dr. I. Peson, Dr. V. Swain
Oral Surgeon	Dr. L. McFadden
Plastic Surgeon	Dr. L. Ross
Orthodontist	Dr. J. Noble
Dentist	All/ Many
Speech pathologist	Carla Thompson
Audiologist	Diana Dinon
Nurse Coordinator	Cynthia Bonneteau (Nurse Clinician)
Social Worker	Dolores Hagerty
Psychologist	Dr. E. Sigurdson
Administrator	Sheryl Clark (Clerical Administrator / Claims Manager)

**Clinic Contact Information:**

**Address:** Children's Hospital of Winnipeg  
 FW 107 685 William ave.  
 Winnipeg, MB, R3E 0Z2

**Tel:** 204-787-2202  
**Fax:** 204-787-8042  
**Email:** [cbonneteau@exchange.hsc.mb.ca](mailto:cbonneteau@exchange.hsc.mb.ca)

## **The Adult Patient**

Patients must be registered into the program prior to their 18<sup>th</sup> birthday. Dental coverage for patients past 18 years of age is client specific as determined by the CLP/C team. Often times due to skeletal growth, the treatment cannot be concluded prior to 18 years of age and patients remain eligible for dental benefits until their treatment plan is deemed complete.

Once the treatment plan has been completed the patient receives a “cut-off” of dental benefits letter. Patients can still be followed in adulthood. The team plastic surgeon has an adult clinic on site and the oral surgeon and prosthodontist have associated adult practices. In some situations adult patients require further treatment for recurring cleft related issues. Under such circumstances dental benefits may be temporarily reinstated at the discretion of the dental director through an application to a committee.

## **Medical Travel Assistance**

Manitoba Health’s Northern Patient Transportation Program (NPTP) provides financial travel assistance for Manitoba residents in the North that require medical treatment , diagnostic services, qualifying therapeutic services, or medical consultation services that are not available in their home community.

Eligibility under the program is limited to Manitoba residents residing north of the 53 parallel from the Saskatchewan boundary to Lake Winnipeg, and North of the 51 parallel from the Ontario boundary to Lake Winnipeg.

The program subsidizes the cost of transportation for the patient. Under circumstances where a companion or a parent is required to escort the patient, the Program includes provisions that subsidize the companions cost of travel, one night stay in a hotel and meals.

Information regarding the Program can be obtained from the NPTP office in Thompson.

**Thompson NPTP office**  
c/o Thompson General Hospital  
871 Thompson Drive South  
Thompson, MB R8N 0C8  
1 800 290-1098

## Ontario

The Ontario Cleft Lip and Palate/Craniofacial (CLP/C) Program is a model of organization and centralization that continues to evolve as it overcomes the challenges of standardization and patient access to care, in a province of vast geographic territory and population. The program is dynamic with changes and enhancements being made on a continuing basis in order to improve service and quality of care and manage the annual budget. Cleft lip and palate/craniofacial medical and dental services are provided at various designated treatment sites across the province of Ontario.

Hamilton – McMaster Children’s Hospital  
Kingston – Hotel Dieu Hospital  
London – Thames Valley Children’s Centre  
Ottawa – Children’s Hospital of Eastern Ontario  
Toronto – Bloorview Kids Rehab  
Toronto - The Hospital for Sick Children (SickKids)  
Windsor – John McGivney Children’s Centre

The Bloorview CLP/C team, in collaboration with SickKids, also offers annual assessment clinics in Peterborough, Thunder Bay, Sault Ste. Marie, Sudbury and Timmins.

Historically, the CLP/C dental services were funded through the Provincial Cleft Lip and Palate Dental Program. In July 1998, the Ministry of Health sponsored a two-day workshop, with representation from all Ontario CLP/C centres, in order to examine the provincial CLP/C Dental Program. Consequently, the provincial review, known as the “Fonberg Report”, resulted in a gradual expansion of funding of the CLP/C Dental Program as well as an expanded list of eligible diagnoses representing congenital, acquired dental and other facial anomalies. Examples of the eligible dental diagnoses include dentinogenesis imperfecta, severe amelogenesis imperfecta, oligodontia (six or more teeth) and severe enamel hypoplasia. The Fonberg document also outlined standards and guidelines that regulate how the program is administered in the various clinics throughout the province. Standards requirements include that a paediatric dentist serve as dental director in each centre. Dental directors hold annual meetings as well as regular conference calls throughout the year. These meetings serve in the spirit of collaboration to maintain and/or improve both the quality of care and access to care in a fiscal responsible manner.

Over the years, there have been numerous administrative changes to the provincial CLP/C Dental Program. In April 2004, the program transferred from the Ministry of Health and Long Term Care (MoHLTC) Priority Programs to the regional offices of the MoHLTC. The Hospital for Sick Children in Toronto was delegated as the "paymaster" for all seven centres and is responsible for all billing functions. A standardized provincial web-based database was implemented in the fall of 2005 to capture all patients registered with the program in the province, and to collect data for all dental treatment plans submitted and funds drawn by each of the centres.

In January 2005, the province’s Specialized Paediatric Coordinating Council (SPCC) was asked to provide advice to the MoHLTC regarding their proposed organizational model for the program or to suggest an alternative, and to play a role in its implementation. As a result of the SPCC’s recommendation, the CLP/C Operational Advisory Committee (CLP/C - OAC) was formed. This group is comprised of dental directors and senior administrators at each hospital/agency that administers cleft



lip and palate clinics in Ontario. The OAC now reports to the Provincial Council for Maternal and Child Health (which replaced SPCC) regarding changes to the program. It also manages the provincial budget for the program including, where possible, the reallocation of funding between centres, within each calendar year, in order to maximize treatments available to clients throughout the province.

### Registration

There is a formal provincial registration process for the Ontario CLP/C Dental Program. CLP patients are identified at birth and registered immediately thereafter in a hospital setting or through a formal referral process. In all cases a “verification of diagnosis” is generated, reviewed and approved by the respective Dental Director to facilitate acceptance and registration into the program. Information captured includes patient name, address, phone number, date of birth, Ontario Health Insurance Plan (OHIP) number, guardian(s) information, insurance carriers, primary and detailed diagnosis, regional location and date made eligible. Older patients and new Ontario residents, that are under the age of 18, are registered on the provincial database through a referral or by contacting one of the designated centres. Again, eligibility for enrollment into the program will be determined by the Dental Director. As of March 31, 2009, there were 5480 active CLP patients registered with the program. The number of registrations of new and newborn patients with orofacial clefts, are provided in Table 11.

**Table 11. Ontario Cleft Lip and Palate Patient Registration (all seven centres)**

FISCAL YEAR (01 Apr – 31 Mar)	Patients Registered	Newborn Patients
2008/2009	267	170
2007/2008	273	169
2006/2007	310	184

When compared to the number of Ontario births from Statistics Canada, the CLP/C Dental Program’s central registry permits the estimation of orofacial cleft incidence rates (Table 12).

**Table 12. Ontario incidence of orofacial cleft.**

Year (01 Jul – 30 Jun)	Statistics Canada Ontario Births <sup>20</sup>	Incidence of orofacial clefts
2008/2009	140,255*	1.2/1000 births
2007/2008	138,985	1.2/1000 births
2006/2007	136,980	1.3/1000 births

\*preliminary

## Ontario Cleft Lip and Palate/ Craniofacial Dental Program

A standard was outlined in the Fonberg Report regarding dental treatment coverage whereby third party insurance is the first to pay for dental coverage, the program is the second pay at 75% of the remaining costs and the patient/family is responsible for the remaining 25%. The CLP/C Dental Program provides dental funding for specialized dentistry (orthodontics, oral surgery, prosthodontics) for approved treatment plans performed by dental specialists.

**Eligibility:** To be eligible for funding an individual must be:

1. A resident of Ontario in possession of a valid OHIP number, and
2. Diagnosed as having a cleft lip and/or palate, a craniofacial anomaly or other severe acquired or congenital dental dysfunction, and
3. Registered in the program before their 18th birthday.

**Services:** Up to 75% of the pre-approved dental specialist treatment costs not covered by private dental insurance will be covered by The Ontario Cleft Lip and Palate/ Craniofacial Dental Program. Coverage includes all dental treatments and hardware related to the preservation and restoration of dental arches and craniofacial complex. These costs may include:

- Infant orthopaedic
- Orthodontic treatment
- Some restorative dentistry
- Dental prosthetics
- Dental implants and oral surgery not funded under OHIP

Patients are entitled to one course of treatment and will be discharged from the program upon completion of treatment. The Cleft Lip and Palate/Craniofacial Dental Program does not cover the cost of routine dentistry and long-term follow-up care.

**Service Provision:** Certified dental specialists in Ontario.

**Utilization and Expenditures:** Cleft lip and palate patient treatment expenditures, for all seven Ontario centres are represented in Table 13. The data do not include the associated cost of administering the dental program or the dental treatment costs for treating patients with craniofacial anomalies, acquired oral defect and other congenital oral defects.

**Table 13. Ontario cleft lip and palate dental treatment expenditures**

FISCAL YEAR	ORTHODONTIC	ORAL SURGERY	PROSTHO-DONTIC	OTHER DENTAL*	TOTAL EXPENDITURES**
2008/09	\$792,411	\$256,771	\$312,873	\$541,912	\$1,903,968
2007/08	\$725,803	\$259,920	\$280,529	\$442,632	\$1,708,885
2006/07	\$779,409	\$338,476	\$332,418	\$417,208	\$1,867,511

\*Includes all other specialties, multi-discipline treatment planning and assessment costs, feeding and orthopaedic appliances

\*\* On a cash basis

## **Ontario Cleft Lip and Palate Clinics**

### **1. Toronto - Bloorview Kids Rehab Cleft Palate Lip / Craniofacial Clinic**

The longest running CLP/C clinic in Ontario has been operating in Toronto at the Bloorview Kids Rehab Centre (formerly Ontario Crippled Children's Centre and then Hugh MacMillan Medical Center), since the late 1960's. In Toronto and the surrounding area, patients are received by direct referral to the outpatient clinic. In addition to outpatient care, annual clinics are held in northern Ontario locations. Newborn children from Northern Ontario, are usually seen at SickKids Hospital, then referred to Bloorview for follow-up by the Bloorview Kids Rehab Northern Ontario Outreach Program. Older children are referred directly to the Outreach Program. There is daily interaction among team members in the outpatient clinic. In addition, as part of the Northern Outreach Program there are seven full clinic days per year in other cities.

#### **History of the Northern Outreach Dental Program**

In the past, as a consequence of limited availability of services in Northern Ontario, individuals with CLP/C anomalies had to travel considerable distances to access necessary care. In an effort to compensate for the lack of services, the Easter Seal Society of Ontario contracted with Bloorview Kids Rehab (formerly The Hugh MacMillan Medical Center) in the 1970s to provide yearly Cleft Lip and Palate/Craniofacial Dental clinics in four Northern Ontario communities: Sault Ste. Marie, Sudbury, Timmins and Thunder Bay. In 2001, Bloorview initiated an annual clinic in Peterborough to service the adjacent northeastern regions of central Ontario. In 1986, more than a decade following the inception of Bloorview's Northern Outreach Program, the Ontario MoHLTC (formerly the Ontario Ministry of Health) established the CLP/C Dental Program in order to help families cope with the high cost of dental treatment. Around the same time, the Easter Seal Society ceased its funding of the Northern Outreach Program, but the program was able to carry-on using contributed margins from internal CLP/C services. Today, these one to two day clinics provide triage, diagnostic services, treatment planning, coordination of ongoing care, and follow-up to 946 children, adolescents and young adults with craniofacial/dental anomalies.

#### **Makeup of the Outreach Team**

The outreach team is a group of medical and dental specialists and allied healthcare professionals seconded from the CLP/C teams at Bloorview Kids Rehab and SickKids, and led by the Director of Dentistry at Bloorview. The following disciplines, as a minimum, are represented on the team: audiology, nursing, oral and maxillofacial surgery, orthodontics, paediatric dentistry, plastic surgery, prosthodontics, psychology, social work and SLP. The composition of the team is determined by the clinical needs of patients being evaluated; thus additional disciplines are included on the team from time to time including epidemiology, genetic counselling, ophthalmology, otolaryngology and paediatrics.

Several residents and fellows from their respective academic teaching programs take part in the clinics to complement clinical manpower requirements and to augment their clinical experience in provision of cleft lip and palate/craniofacial care.

Volunteers from local service clubs assist with transportation to and from airports, meals, and clinic operations. Coordination of local operations is carried out by a part time coordinator employed by Bloorview. Local clinicians are encouraged to attend clinics to take part in the assessment of their own

patients, empowering them to provide rehabilitation services more effectively in their own communities and reducing the frequency of review required at outreach clinics.

**Clinics are held at the following facilities:**

- |                      |  |
|----------------------|--|
| 1. Thunder Bay:      | George Jeffrey Children’s Center                 |
| 2. Sudbury:          | Cambrian College                                 |
| 3. Sault Ste. Marie: | Children’s Rehabilitation Centre Algoma          |
| 4. Timmins:          | Cochrane Temiskaming Children’s Treatment Center |
| 5. Peterborough:     | Five Counties Children’s Center                  |

**Eligibility and Timing of Assessment by Outreach Team**

Individuals diagnosed as having a cleft lip and/or palate, a craniofacial anomaly or other severe dental anomaly and who are registered with the CLP/C Dental Program, or who have been referred by a dentist or physician for evaluation of eligibility for financial assistance through the program, are assessed by the outreach team.

Outreach team assessments begin shortly after birth and continue until the completion of growth, when the individual attains full maturity and is discharged from the Cleft Lip and Palate/Craniofacial Dental Program. Patients are seen at designated intervals during their treatment by the team to monitor the progress of their treatment. Present staffing and infrastructure levels allow the team to see each patient, on average, every other year.

**Future Projects**

An initiative between Bloorview Kids Rehab and Ontario Telemedicine Network is presently underway to test the use of two-way videoconferencing systems and the latest tele-diagnostic instruments, including high-resolution patient examination cameras and digital imaging facilities, to transfer data between team members in Toronto and northern outreach clinics and other remote sites across the province. The use of telemedicine will further enhance access and quality of healthcare delivered to children with cleft lip and palate and other craniofacial anomalies in northern Ontario.

<b>Bloorview Cleft Lip and Palate / Craniofacial Team</b>	
<b>Dental Director</b>	<b>Dr. Robert Carmichael, Prosthodontist</b>
Geneticist	By referral to Sick Kids
Paediatrician	Dr. Golda Mil-Manson, Dr. Glenn Berall
Otolaryngologist	Dr. Paulo Campisi
Paediatric Dentist	Dr. Dan Semenuk, Dr. Peter Judd, Dr. Edward Barrett Dr. Randi Fratkin
Prosthodontist	Dr. Robert Carmichael
Oral Surgeon	Dr. George Sandor, Dr. Iain Nish
Plastic Surgeon	Dr. Christopher Forrest, Dr. Ronald Zuker, Dr. Howard Clarke, Dr. David Fisher, Dr. John Phillips
Orthodontist	Dr. Bryan Tompson, Dr. Akbar Rawji, Dr. Shervin Abbaszadeh
Speech Pathologist	Ava-Lee Kotler, Sharon McConney-Ellis, Simone Fischbach Jennifer Allegro, Fran Margar-Bacal, Maryann Witzel
Audiologist	Cleo Audet Halde, Sarah Snieder
Nurse	Cindy Guernsey, Alan George, Alison Miller
Social Worker	Heather Beveridge, Kim Tiemens
Psychologist	Marla Bigel
Other	Carmen Bazinett (Northern Outreach Program Coord) Doreen Scott-Rolf (Bloorview Clinic coord) Sharon Cowling (Finance Coord)
Administrator	

Clinic Contact Information:

Address: Bloorview Kids Rehab  
150 Kilgour Road  
Toronto, ON, M4G 1R8

Tel: 416-425-6220 (ext 3465)  
Fax: 416-424-3839  
Email: [rcarmichael@bloorview.ca](mailto:rcarmichael@bloorview.ca)

## **2. Hamilton - McMaster Children's Hospital Cleft Lip and Palate Clinic**

The regional Cleft Lip and Palate Team has been operating at the McMaster Children's Hospital since 1987. Prenatal patients are referred to the team from the community or via the prenatal diagnosis clinic. The clinical coordinator sees the mother for an initial appointment. The mother is registered with the team until the time of birth. After birth, the child is registered with the team and province. A similar process is used for adoptions from developing countries.

Newborn babies are seen in the hospital within 24 to 48 hours following birth. Once they are registered, the team care plan is initiated. From birth to 2 years, patients are seen for individual appointments with various health care providers. Between 2 and 6 years of age the patient will attend multidisciplinary clinics (developmental pediatrics, speech and audiology) with other discipline visits, as needed. Patients 7 years and older attend multidisciplinary clinics with the entire team. Anticipatory surveillance is provided from birth to 22 years of age. The team meets for 10 full team clinics and 26 core team (paediatrics, speech, audiology) clinics in a year.

Individuals identified later in life or who move to the area from out of province or outside the country are referred from the community. They are booked into the care plan clinic most appropriate to their age and needs. In most cases, a medical referral is required.

A full summary of services and patient educational materials is available on the hospital website:

<http://www.mcmasterchildrenshospital.ca>

Type "cleft" in the search bar and click on "patient education materials".

<b>McMaster Children's Hospital Cleft Lip and Palate Team</b>	
<b>Dental Director</b>	<b>Dr. Peter Pannozzo, Paediatric Dentist</b>
Geneticist	
Paediatrician	Dr. K. Harman (Medical director)
Otolaryngologist	Dr. E. Jeney
Paediatric Dentist	Dr. Peter Pannozzo
Prosthodontist	Dr. M. Al Mardini
Oral Surgeon	Dr. B. Harnett
Plastic Surgeon	Dr. N. Strumas
Orthodontist	Dr. R Tocchio
Dentist	
Speech Pathologist	Brenda Murphy-Anderson, Christina Mellies
Audiologist	Carol Pavey
Coordinator	Susan Eastwood
Social Worker	Alan Feldman
Psychologist	
Other	Dorothy Ram (secretary)
Administrator	

Clinic Contact Information:

Address: Cleft Lip and Palate Team  
 McMaster Children's Hospital / HHS Chedoke Site Evel 451  
 PO Box 2000  
 Hamilton , ON, L8N 3Z5

Tel: 905-521-2100 (ext 77210)

Fax: 905-521-7953

Email: [eastwood@hsc.ca](mailto:eastwood@hsc.ca)

### **3. Windsor - John McGivney Children's Centre Maxillofacial-Speech Clinic**

The Maxillofacial-Speech Clinic at the John McGivney Children's Centre in Windsor, has been caring for patients with oral clefts since 1979. Patients are typically referred at birth. Windsor Regional Hospital will contact the John McGivney Children's Centre when an infant is born with a cleft lip and/or palate. The Coordinator/SLP will provide consultation to the family and nursing staff at the hospital after birth and will also provide the family with information regarding the provincial CLP/C Dental Program. The plastic surgeon and the dental director will provide an assessment and consultation at the hospital or shortly after the child is discharged.

Clients requiring dental diagnoses and craniofacial diagnoses are typically referred later by clinicians, dental specialists, physicians and/or parents. These individuals are registered once they have been seen for an eligibility screening assessment. Four to five dental screening clinics are held annually, involving the dental director and coordinator exclusively, to determine eligibility for registration with the program.

The Maxillofacial-Speech Clinic follows patients from birth to 22 years of age. On an annual basis the team meets for approximately twelve multi-disciplinary clinics, ten dental clinics (ages 7+), two plastics clinics (ages 0-7), and two prosthodontic clinics.



<b>John McGivney Children's Maxillofacial-Speech Team</b>	
<b>Dental Director</b>	<b>Dr. Tom Oper, Paediatric Dentist</b>
Geneticist	
Paediatrician	Dr. Beth Macklin (developmental pediatrician)
Otolaryngologist	
Paediatric Dentist	Dr. Tom Oper,
Prosthodontist	Dr. Herman Kupeyan
Oral Surgeon	Dr. Richard Stapleford
Plastic Surgeon	Dr. Bruce Snowdon
Orthodontist	Dr. Gary Cooper Dr. Frank Janisse
Dentist	
Speech Pathologist	Tonia Bryans, Nancy Holmes
Audiologist	Kirstie MacDonald
Coordinator	Tonia Bryans (SLP)
Social Worker	
Psychologist	
Other	Sharyn Zerbin, (Behavioural Consultant)
Administrator	Dawn Mulder

**Clinic Contact Information:**

Address: John McGivney Children's Centre  
Maxillofacial-Speech Clinic  
12050 Arbour Street  
Tecumseh, ON, N8N 1N8

Tel: 519-979-7788  
Fax: 519-979-0578  
Email: [tonia.bryans@jmccentre.ca](mailto:tonia.bryans@jmccentre.ca)

#### **4. Toronto – The Hospital for Sick Children Cleft Lip and Palate / Craniofacial Clinic**

The CLP Program at the Hospital for Sick Children is one of the largest programs in North America. The program receives approximately 120 newborn patients every year and cares for over 3000 patients. Newborn patients are referred to the craniofacial team at birth at which time involvement of specific specialties is determined. Referrals from the community or patient transfers from other provinces are booked for a full team assessment with the Craniofacial Team.

Full team assessments are scheduled every Monday and normally include representation from all specialties. The assigned team for the Monday will then meet at the end of the day to review all cases. Patients with cleft lip and/or palate receive treatment throughout the week in the hospital.

A full summary of services and patient educational materials is available on the hospital website:

<http://www.sickkids.ca/cleftlip/index.html>

<b>The Hospital for Sick Children Cleft Lip and Palate / Craniofacial Team</b>	
<b>Dental Director</b>	<b>Dr. Peter Judd, Paediatric dentist</b>
Geneticist	R. Klatt
Prenatalist	Dr. D. Chitayat
Paediatrician	Dr. M. Sgro, Dr. T. Barozzino
Otolaryngologist	Dr. W. Crysdale, Dr. V. Forte, Dr. J. Friedberg, Dr. B. Papsin
Paediatric Dentist	Dr. E. Barrett, Dr. Peter Judd, Dr. M. Casas, Dr. R. Fratkin Dr. Dave Farkouh, Dr. Shonna Masse
Prosthodontist	Dr. Robert Carmichael
Oral Surgeon	Dr. George Sandor, Dr. Iain Nish, Marshall Freilich
Plastic Surgeon	Dr. D. Fisher, Dr. J. Phillips, Dr. C Forest, Dr. H. Clarke Dr. R. Zuker
Orthodontist	Dr. B. Thompson, Dr. A. Dagys, Dr. J. Daskalogiannakis Dr. N. Shapera, Dr. M. Taylor, Dr. B. Vendittelli, Dr. A. Chen, Dr. J Britton, Dr. S Naslenas
Dentist	
Speech Pathologist	Paula Klaiman, Simone Fischbach, Fran Margar-Bacal
Audiologist	Jamie Grew
Nurse Coordinator	Cindy Guernsey
Social Worker	Heather Beveridge, Kim Tiemens
Psychiatrist	Dr. N. Keyhan
Other	J. Nijhuis (Dietitian) M. Bigel (Neuropsychologist)
Administrator	Cindy Guernsey

**Clinic Contact Information:**

**Address:** Cindy Guernsey, Cleft Lip and Palate Coordinator  
Hospital for Sick Children  
555 University Avenue  
Toronto, ON, M5G 1X8

**Tel:** 416-813-7491  
**Fax:** 416-813-6637  
**Email:** [cindy.guernsey@sickkids.ca](mailto:cindy.guernsey@sickkids.ca)

## **5. London - Thames Valley Children's Centre Cleft Lip and Palate Clinic**

The multidisciplinary CLP team in London was first assembled approximately thirty years ago. It is now a regional service organized through Thames Valley Children's Centre (TVCC). Referrals come from London/Middlesex and other counties in South-Western Ontario.

Typically, referral requests come from hospitals once an infant is born and identified as being in need of service. Initial contact for newborn referrals is usually by telephone or by fax. The Social Worker or SLP on the CLP team will provide the physician's office with some initial guidance regarding infant feeding and the scheduling of a surgical consult with the team. The parents of the newborn will receive a call from TVCC within one or two days following the referral.

When the team receives a pre-natal referral from a physician, the parents are offered an appointment to speak with the Social Worker and the SLP on the team in order to discuss general information regarding the treatment of CLP. The team also receives referrals for preschoolers and older children from physicians and dental practitioners.

Multidisciplinary clinics are held 14 times per year at TVCC with sixteen patients attending each clinic. These are assessment and treatment/care plan management clinics. In addition, individual discipline treatments are provided by team members through private offices. Actual dental treatments as well as surgical interventions occur outside of the clinics through many community practitioners. The team maintains communication with area providers through telephone contact and the distribution of a comprehensive clinic report. A clinic feedback form is also available for community practitioners to submit their clinical information about the patient or bring forward concerns they would like the team to address. The team is currently monitoring and providing care for 550 active patients.

A summary of services is available on the hospital website at the TVCC website:

<http://www.tvcc.on.ca/cleft-lip-palate-clinic-3.htm>

<b>Thames Valley Children's Centre Cleft Lip and Palate Team</b>	
<b>Dental Director</b>	Dr. Olaf Plotzke, Paediatric Dentist
Geneticist	
Paediatrician	
Otolaryngologist	Dr. Murad Husein
Paediatric Dentist	Dr. Olaf Plotzke
Prosthodontist	
Oral Surgeon	
Plastic Surgeon	Dr. Damir Matic
Orthodontist	Dr. Tim Foley
Dentist	
Speech Pathologist	Anne Dworschak-Stolkan
Audiologist	
Nurse Coordinator	
Social Worker	Lori Ksonzyna
Psychiatrist	
Other	Kim Styles (clinical assistant)
Administrator	Brent Duncan

Clinic Contact information:

**Address :**      **Thames Valley Children's Centre Cleft Lip and Palate Clinic**  
779 Baseline Rd. E  
London, ON, N6C 5Y6

Tel:                519-685-8680  
Fax:                519-685-8679  
Email:             [brent.duncan@tvcc.on.ca](mailto:brent.duncan@tvcc.on.ca)

## **6. Ottawa - Children's Hospital of Eastern Ontario Cleft Lip and Palate Clinic**

The CLP Team has been operating in the Ottawa region at the Children's Hospital of Eastern Ontario (CHEO) since 1974. Referrals come from community physicians, obstetricians, adoption agencies as well as community hospitals in Ottawa/Carleton and surrounding communities in Eastern Ontario and Western Quebec.

The team's nurse coordinator makes the initial telephone contact with professionals and families. Prenatal clients are typically referred to genetics by their obstetrician and meet with the nurse coordinator who provides parents with initial information regarding multidisciplinary treatment. Newborns are seen in the area hospitals within 2 days and are assessed for feeding by the nurse coordinator, who then initiates the team care plan.

A consult is scheduled with the plastic surgeon within 2 weeks of birth and with the CHEO dental clinic, if NAM appliance treatment is to be implemented. Assessment by audiology/otolaryngology occurs at 3 months of age, and the child is followed every 3 to 6 months as required. The initial speech assessment is scheduled 2 months following palate repair. For pre-school age children, treatment is provided by the Speech Pathologist at CHEO and monitoring occurs yearly as required. School age children are offered this service in the community by the school board SLP. Quebec clients can access speech therapy treatment through CHEO, the hospital in Gatineau (Centre Hospitalier des Vallées de l'Outaouais), or the school board.

Multidisciplinary conferences are held ten times per year at the CHEO. Children are seen at 4 to 5 years of age and every 2 years following, as required. The team is comprised of a paediatric dentist, otolaryngologist, orthodontist, speech pathologist, plastic surgeon and oral surgeon.

Orthodontic treatment for patients with CLP is provided at the CHEO three mornings per week. Many patients are also treated in private orthodontic practice. Dental treatment is provided by paediatric dentists and specialists in the CHEO dental clinic as well as by dental specialists in the community. Treatment is typically completed by age 22.

Children who are identified later in life or individuals arriving from out of province are referred by community medical or dental practitioners. They are assessed in the CHEO dental clinic and are eligible for registration in the CLP/C Program up to 18 years of age.

Patients from Western Quebec are seen at CHEO but are funded by the Quebec program, through Saint Justine Hospital in Montreal, to a maximum of \$3700.00 for orthodontics. Parents of Quebec patients that require the NAM appliance and therapy are required to pay for this treatment at a cost of \$3000.00. This poses a hardship for many families with children requiring complex treatment.

<b>Children's Hospital of Eastern Ontario Cleft Lip and Palate Team</b>	
<b>Dental Director</b>	<b>Dr. B. Carol Janik, Paediatric Dentist</b>
Geneticist	
Paediatrician	
Otolaryngologist	Dr. Johnna MacCormick (Chief), Dr. Matthew Bromwich Dr. Jean Phillippe Vaccani
Paediatric Dentist	Dr. B. Carol Janik, Dr. Stephanie Lauziere
Prosthodontist	Dr. John Cox
Oral Surgeon	Dr. Samuel Kucey, Dr. Kevin Butterfield
Plastic Surgeon	Dr. Mary Jean Duncan (Medical Director), Dr. Paul Benoit, Dr. Yvonne Ying
Orthodontist	Dr. Mark Luden, Dr. Jessica Tan, Dr. Sharleen Tan
Dentist	
Speech Pathologist	Sussie Lin, Anique Gagan
Audiologist	Linda Morin
Nurse Coordinator	Sue Hunt
Social Worker	
Psychiatrist	
Other	Melanie Rochon (Dental Hygienist), Nathalie Winton (Treatment Coordinator)
Administrator	Tammy Degiovanni

#### Clinic Contact Information

Address: Children's Hospital of Eastern Ontario Cleft Palate Clinic  
401 Smyth Road  
Ottawa, Ontario, K1H 8L1

Tel: 613-737-7600 Ext. 1565

Fax: 613-738-4201

Email: [nwinton@cheo.on.ca](mailto:nwinton@cheo.on.ca)

## **7. Kingston- Hotel Dieu Hospital Cleft Lip and Palate Clinic**

The Kingston clinic has been accepting referrals since 1989 from the South Eastern Ontario region, which serves an estimated population base of 500,000 people. New patients with oral clefts are referred to the clinic from either their regional hospital, primary care physician or by Kingston General Hospital Paediatrics. Parents of newborn infants are contacted by a team member to assess feeding issues. They will then be scheduled for the next CLP clinic or by the team plastic surgeon immediately, as the need dictates.

The multidisciplinary team meets approximately eight times per year with approximately 8-10 children attending each clinic. The team is composed of a paediatric dentist, orthodontist, plastic surgeon, paediatrician, otolaryngologist, speech pathologist, and audiologist. Assessments are made by each service followed by a team meeting to determine a child's progress and treatment plan. An information summary with recommendations is produced by the Dental Director and mailed to the family, team members and all health care providers involved with a child's care. Patients are followed until all surgical, orthodontic and prosthetic needs have been addressed, and are usually discharged between the ages of 18 and 22. The team currently manages 235 patients.

The Hotel Dieu Hospital does not have a dental clinic and all dental/orthodontic related services are provided in the private sector by dental specialists.



<b>Kingston- Hotel Dieu Hospital Cleft Lip and Palate Team</b>	
<b>Dental Director</b>	<b>Dr.Paul MacDonald, Paediatric Dentist</b>
Geneticist	
Paediatrician	Dr.Sheila Kiruluta
Otolaryngologist	Dr. Don MacNaughton
Paediatric Dentist	Dr.Paul MacDonald,
Prosthodontist	
Oral Surgeon	
Plastic Surgeon	Dr. John Davidson
Orthodontist	Dr. Tim Agapus
Dentist	
Speech Pathologist	Stacey Sedore
Audiologist	Paula Varrette-Cerre
Nurse Coordinator	Linda Riley
Social Worker	
Psychiatrist	
Other	
Administrator	Diane Cornish

#### Clinic Contact Information

Address: Diane Cornish  
Hotel Dieu Hospital, Murray Building  
156 Brock Street  
Ottawa, Ontario, K7L 5G2

Tel: 613-544-3400 Ext. 3624

Fax: 613-544-7461

Email: [cornishd@hdh.kari.net](mailto:cornishd@hdh.kari.net)

## **The Adult Patient**

Patients must be registered prior to their 18th birthday to be eligible for dental funding. The aim of the program is to provide one course of complete treatment within a reasonable period of time. Typically, most treatment plans are completed prior to a patient's 18<sup>th</sup> birthday. Delay in craniofacial maturity, or if the patient is a late registrant, may extend treatment into the early twenties. Patients are discharged from the program once their dental treatment is complete. Once they are discharged, there are very limited coordinated team services available to adults, and they will be referred to the community for long term care.

In exceptional cases and if successfully appealed by the provincial dental directors with the CLP/C Dental Program, there may be eligibility discretion for over age patients. An appeals committee, composed of three dental directors and an alternate, meets quarterly or on an ad hoc basis to deal with grievances.

## **Medical Travel Assistance**

The MoHLTC funds and administers the Northern Health Travel Grant (NHTG) Program to help defray some of the costs incurred by Northern Ontario residents who must travel long distances within Ontario or Manitoba to receive medically insured services, which are not available in their community. Effective July 1, 2007, the NHTG Program pays 41 cents per kilometer, based on return road distance with a 100km deductible per trip. Travel may be by train, plane, bus or car. Furthermore, the Program will provide an accommodation allowance of \$100 for each eligible trip a patient makes. There is no compensation for meals.

Any OHIP insured resident of Northern Ontario, who has been referred by a northern practitioner to the nearest physician specialist or health facility approved by the ministry, can apply for a travel grant. In addition, an escort is also eligible to apply for a grant when the patient being referred is under 16 years of age or when the referring practitioner deems that the patient is unable to travel without a companion.

Information regarding the NHTG Program is available at the Ministry of Health and Long Term Care website:

<http://www.health.gov.on.ca/english/public/pub/ohip/northern.html>

## Quebec

Because the Province of Quebec provides greater support for families, its social programs are generally considered more progressive than those of other provinces. For example, the creation of a reduced-contribution program in 1997 for children between the ages of zero and five in childcare centres resulted in universal, affordable daycare services and enabled working parents to rejoin the workforce. Furthermore, since 2006, the Quebec Parental Insurance Plan (QPIP) has granted new parents 52 weeks of parental leave. It can be argued that establishing childcare centres and extending parental leave has contributed to the astonishing 17% increase in Quebec's birth rate since the low of 2004. As the provincial birth rate continues to rise, it will likely also translate into an increase in the number of babies born with cleft lip or palate each year.

Quebec has three clinics that provide medical and dental services for patients with anomalies such as cleft lip or palate. The oldest cleft palate clinic opened its doors in 1955 at the Montreal Children's Hospital. The second, which is currently the largest cleft palate clinic in the province, was established at Hôpital Sainte-Justine in 1964. Shortly thereafter, in 1965, a cleft lip and palate clinic opened at the Centre hospitalier universitaire de Québec (CHUQ). In addition, the Montreal Children's Hospital and Hôpital Sainte-Justine both have multidisciplinary craniofacial teams that treat patients with craniofacial anomalies other than cleft palate. The multidisciplinary team at CHUQ treats children from the Quebec City area and the eastern part of the province who have cleft lip or palate or other orofacial anomalies. The team is considered a maxillofacial team rather than a craniofacial team because it does not have a neurosurgeon.

Each clinic maintains its own database on patients referred to it at birth or at a later stage. The number of patients registered at each clinic is shown in Table 14.

**Table 14. Quebec Cleft Palate Clinic Registration 2005-2009**

YEAR	Hôpital Sainte-Justine (newborns)	Montreal Children's Hospital (newborns)	Centre hospitalier universitaire de Québec (CHUQ) (newborns)
2009 (as of June)	N/A (30)	27 (13)	22 (17)
2008	93 (27)	52 (24)	28 (21)
2007	67 (45)	40 (22)	27 (22)
2006	78 (49)	34 (18)	26 (18)
2005	63 (52)	44 (20)	20 (17)

### Quebec Cleft Lip and Palate Dental Benefit Programs

The Province of Quebec has always been a leader in the planning and delivery of public dental services. Since the early 1980s, the Dental Services Program for Children (PSDE) has provided dental services for children up to the age of 15. However, as in most provinces that offer dental services for children, PSDE services have been reduced and now provide coverage only to children under the age of 10. Children with cleft palate in this age group are eligible for dental services insured under the PSDE, as are all children in Quebec.

While Quebec is more forward-thinking in its oral health and social programs, the province appears to spend less on dental treatments for cleft palate, given its birth rate, than almost all the other provinces. The lack of sufficient funding for dental services was mentioned by the three clinics in their answers to the study questionnaire. Their answers also highlighted the disparities that exist between the clinics with regard to insured dental services for their patient populations. In order to understand which dental services each clinic offers at no cost to the patient, it must first be understood how the government funding is distributed.

The Quebec Department of Health and Social Services (MSSS) funds dental treatment for patients with clefts affecting the alveolus and/or the palate. The funds are intended to cover the cost of dental arch expansion, bone grafts, orthodontic treatment and a removable prosthesis for patients under the age of 21. In order to qualify for funding, children must have a cleft palate or a cleft lip and palate and present with a malocclusion associated with the cleft. Malocclusions that are not related to the cleft are not treated. The orthodontist is responsible for determining the patient's eligibility.

MSSS states that it spent \$460,000 to fund the province's three cleft lip and palate clinics in 2008. The funding was distributed in the form of three separate grants to the three designated hospitals providing care. The way each hospital spends the money has a major impact on which dental services each clinic can provide free of charge and which services patients will receive at no cost. Depending on what other resources are available at the hospital, each clinic finds its own way to optimize the funds allocated to it. As a result, patients may receive services where the insured amount varies depending on

which hospital they go to for treatment and follow-up. Below is an explanation of the Quebec Dental Services Program for Children, the operating funds for each of the three cleft palate clinics and the insured services they offer.

### **1. Dental Services Program for Children (PSDE)**

**Eligibility:** This program is offered to all Quebec children under the age of 10.

**Services:** Insured services include one examination per year, diagnostic services, endodontic and restoration treatments, and extractions. Costs related to cleaning and fluoride application are not covered.

**Service Provision:** Dentists provide treatments in private practice and/or in hospitals.

### **2. Cleft Palate Dental Treatment Program at the Montreal Children's Hospital**

The total annual budget for the cleft palate treatment program was \$118,000 for 2008. This covered the salary of one full-time clinic coordinator, two orthodontists (six days a month combined), a dental assistant for each orthodontist, and a dental hygienist working one day a month, as well as the cost of all the orthodontic and clinic material, instruments, and laboratory fees. In 2008, the annual budget made it possible for the team to provide free ongoing orthodontic treatment to 180 cleft lip and palate patients. The clinic was able to provide orthodontic services to all of these patients even on a small budget largely because of the commitment of the two orthodontists, who have worked with the team for many years and accept low fees on principle rather than the full fees charged by specialists.

The government does not fund dental care for patients with other craniofacial anomalies. Orthodontic treatment for children born with craniofacial anomalies, other than cleft palate, that affect dentition are not covered by insurance; however, the clinic is able to provide on-site orthodontic services for these patients thanks to funding from various donations. At one point the clinic covered part of the cost of orthodontics and prosthodontics for patients in remote areas who received treatment in private practice. Unfortunately, this support had to be discontinued due to financial constraints. Most patients living in remote areas who have to come to the clinic for orthodontic care may qualify for travel funding from various social services.

#### **What is covered:**

- a) *Only orthodontic treatment given at the Montreal Children's Hospital is covered at 100% of the cost. Children living in remote areas must come to the clinic for treatment. The clinic has never been authorized to submit claims to parents' private insurance for the amounts that may be agreed upon for orthodontics on their family plan; and*
- b) *Palatal obturators or feeding appliances, as required.*

#### **What is not covered:**

- a) *Payment for treatment by an orthodontist in private practice;*
- b) *Fees charged by other dental specialists or for other treatments (e.g. prosthodontics, periodontics); and*
- c) *Laboratory fees for nasoalveolar moulding appliances.*

### **3. Cleft Palate Dental Treatment Program at Hôpital Sainte-Justine**

The provincial funding from MSSS for Sainte-Justine is higher than for the two other provincial cleft palate clinics. The Hôpital Sainte-Justine clinic uses these funds to provide care at the hospital and partly fund dental services provided by private practitioners to patients living in remote areas or being treated by the Cleft Palate Clinic at the Children's Hospital of Eastern Ontario (CHEO).

In addition, the clinic at Hôpital Sainte-Justine employs and pays three part-time orthodontists at a fixed daily rate, a paediatric dentist who examines children at each follow-up appointment, and dental assistants. The clinic also pays for all the instruments and orthodontic and clinic material, as well as the related laboratory fees. The clinic also strives to limit costs because provincial funding for dental rehabilitation has fallen behind in relation to the changing level of dental care and the increase in related treatment costs.

#### **What is covered:**

- a) *The full cost of orthodontic treatment when it is given at Sainte-Justine. The clinic has never been authorized to submit claims to parents' private insurance for the amounts that may be agreed upon for orthodontics on their family plan;*
- b) *When orthodontic treatment is provided outside of Sainte-Justine, orthodontic fees will be reimbursed up to a maximum. The amounts are set at \$1,500 for an isolated cleft lip, \$750 for the expansion phase and \$2,950 for a full cleft lip and palate. The treating orthodontist must submit a treatment plan to the cleft palate clinic for approval. Children in Quebec being treated by the multidisciplinary team at CHEO receive the same amounts without their treatment plan needing to be approved;*
- c) *Up to \$800 for removable or fixed prosthetics, or for a prosthesis over dental implants. The prosthodontist from the Université de Montréal assesses these children at HSJ and treatment is then provided at the university. Children can have access to complex prosthodontic treatments there (e.g. osseointegrated implants) if their parents are able to pay the additional sum required;*
- d) *Palatal obturators or feeding appliances, as required; and*
- e) *Pre-surgical orthodontics and nasoalveolar moulding appliances. There is no specific budget for pre-surgical orthodontics because the majority of patients are treated on-site at HSJ and the orthodontics and laboratory costs are included with the other costs.*

#### **What is not covered:**

- a) *Certain oral surgery treatments (e.g. exposure of impacted teeth) and periodontal treatment are not covered.*
- b) *There has never been a budget for pre-surgical orthodontics fees and nasoalveolar moulding appliances for patients in the region.*

**Expenditures:** Expenditures on the orthodontic, paediatric dentistry and prosthodontic components of the cleft palate clinic at Hôpital Ste-Justine and on dental care for Quebec children with clefts who are registered in the region and at CHEO are shown in Table 15.

**Table 15. Expenditures for Dental Treatment at CHUQ**

YEAR	HSJ Expenditures	Regional and CHEO Expenditures	TOTAL
2008-09	\$261,475.18	\$27,176.15	\$288,651.33
2007-08	\$291,818.74	\$14,440.00	\$306,258.74
2006-07	\$334,662.37	\$26,105.67	\$360,768.04
2005-06	\$156,561.93	\$6,828.00	\$163,389.93
2004-05	\$266,413.67	\$24,275.00	\$290,688.67
2003-04	\$239,789.97	\$19,400.91	\$259,190.88

#### **4. Cleft Palate Dental Treatment Program at CHUQ**

The clinic received \$115,000 for the provision of orthodontic and prosthetic services to its patients in 2008. Unlike the other two cleft palate treatment centres in Quebec, the CHUQ orofacial malformation committee does not employ practising orthodontists at the hospital. For this reason, orthodontic and prosthetic treatments are given in private practice. Patients living in the Quebec City area receive treatment from orthodontists on the multidisciplinary orofacial team. Patients living in remote areas can receive care in their local community, but the treatment plan and cost must be approved by the team.

In 2003, two maxillofacial oral surgeons were added to the team, expanding the treatment services offered and the clientele served. Bone grafts, orthognatic surgery and osteodistraktion are now performed on patients with maxillopalatal clefts who require such procedures. Children with orofacial anomalies other than cleft palate are now examined by the team and are able to benefit from its multidisciplinary expertise. However, it is up to the parents to pay the orthodontic fees and for the prosthetics, because the government does not provide additional funding for these patients.

In 2008, the team submitted a request to the Quebec Department of Health for additional funding to increase operating room hours for maxillofacial surgery and to add more coordination time and speech pathology services. The team also plans to submit a request for additional funding to extend dental coverage to children with orofacial anomalies other than cleft palate and to increase coverage of prosthetic treatment for cleft palate patients.

#### ***What is covered:***

- a) Orthodontic treatment is fully covered. Patients living in the Quebec City area are usually examined by one of the team's orthodontists in private practice. When orthodontic treatment is provided outside of the Quebec City area, the treating orthodontist must submit a treatment plan to the orofacial malformation committee for approval;*
- b) Up to \$750 for prosthetic treatment services, which may include crowns or removable or fixed prostheses;*
- c) Up to \$750 for the cost of dental implants;*
- d) Palatal obturators or feeding appliances, as required; and*
- e) Pre-surgical orthodontics and nasopalveolar moulding appliances.*



**What is not covered:**

- a) Certain oral surgical treatments (e.g. exposure of impacted teeth) or periodontal treatment.

**Utilization and expenditures:** Program utilization and expenditures are shown in Table 16.

**Table 16. CHUQ Dental Treatment Expenditures**

YEAR	Cost of Prosthodontics* (number of patients)	Cost of Orthodontics (number of patients)	Total Expenditures
2008	\$21,750 (134)	\$91,739 (56)	\$113,489
2007	\$30,344 (105)	\$85,367 (62)	\$115,711
2006	\$16,379 (117)	\$91,220 (72)	\$107,599

*\*Includes cost of palatal obturators*

## **Cleft Palate Clinics in Quebec**

### **1. Montreal Children's Hospital Cleft Lip and Palate / Craniofacial Clinic**

Parents can be referred to the clinic once a cleft is observed on the ultrasound, which is generally at the 20th week of pregnancy. The parents attend a pre-natal consultation and receive instructions and feeding bottles. Once the baby is born, the nursery calls to book the baby's first appointment, which takes place in the first or second week following birth. The first consultation is held with the clinic's paediatrician, plastic surgeon and orthodontist, who will determine whether nasoalveolar moulding will be necessary. The patient then receives weekly follow-up by the orthodontist in charge of this treatment. At the age of one month, the child is referred to audiology and ENT.

Follow-up assessments and treatment are planned according to the protocol and the patient's needs. All treatments, including orthodontic treatments, are given at the Montreal Children's Hospital, where there is daily interaction among the team members. The clinic coordinator supervises the management of patient documents and the contents of files and organizes appointments. The whole team meets about four times a year to examine complex cases and those of patients with serious conditions.

Most patient visits will take place with the orthodontist as the patient grows. There are approximately 60 orthodontic clinic days each year. The clinic currently has 180 patients receiving active orthodontic treatment and 60 patients in the treatment retention phase. The team currently provides care to over 450 active patients.

<b>Montreal Children's Hospital Cleft Lip and Palate / Craniofacial Team</b>	
<b>Team Leader</b>	<b>Dr. Mirko Gilardino, Plastic Surgeon</b>
Geneticist	On referral
Paediatrician	Dr. Diane Munz
Otolaryngologists	Dr. S. Daniel, Dr. L. Nguyen, Dr. M. Schloss, Dr. R. Shapiro, Dr. M. Manoukian, Dr. T. Tewfik
Paediatric Dentist	
Prosthodontist	
Oral and Maxillofacial Surgeons	Dr. Richard Emery, Dr. Deborah Iera
Plastic Surgeons	Dr. Mirko Gilardino, Dr. Lucie Lessard, Dr. H.B. Williams
Orthodontists	Dr. Jon Kapala, Dr. Madelaine Shildkraut Dr. Broula Jamal
Neurosurgeons	Dr. J.P. Farmer, Dr. J. Montes, Dr. J. Atkinson
Speech Pathologist	Élaine Pelland-Blais
Audiologist	Louise Miller
Coordinator	Maria Coirazza
Social Worker	On referral
Psychologist	On referral
Other	
Administrator	

**Clinic Contact Information:**

Address: Montreal Children's Hospital  
2300 Tupper St., Room C-1132  
Montreal QC H3H 1P3

Tel.: 514-412-4400, ext. 22517

Fax:

E-mail: [maria.coirazza@muhc.mcgill.ca](mailto:maria.coirazza@muhc.mcgill.ca)

## 2. Hôpital Sainte-Justine Cleft Palate Clinic

The cleft palate team meets twice a week from 1:00 to 1:30 p.m. to discuss the cases of patients who have been examined individually by team members over the course of the morning. On average, four patient cases are reviewed during a team meeting. The entire team then meets with the family to present the assessment and proposed treatment plan.

The clinic sees the majority of cleft lip and palate patients in Quebec. It is estimated that in a given week, 20% of the operating room hours for plastic surgery are dedicated to children with cleft palate.

The stages of patient care and the involvement of health care providers at each stage generally follow this timeline:

Pre-natal assessment – Geneticist and plastic surgeon;

Newborn examination – Nurse, plastic surgeon and preoperative orthodontist (nasalveolar moulding);

At 3 months – cleft lip surgery – plastic surgeon;

Postoperative examinations – Otolaryngologist and paediatrician;

At 1 year – cleft palate surgery – plastic surgeon;

Postoperative examinations – Otolaryngologist and paediatrician;

At 2 years – first meeting with multidisciplinary team, then follow-up every 2 years until discharge;

From 8 to 10 years – palatal expansion in mixed dentition stage and alveolar bone graft as needed;

Orthodontics with or without orthognathic surgery;

From 3 to 18 years – pharyngoplasty, speech pathologist and psychological services as needed;

Rhinoplasty, once skeletal growth is complete.

<b>Hôpital Sainte-Justine Cleft Lip/Palate Team</b>	
<b>Team Leader</b>	<b>Dr. L. Caouette Laberge, Plastic Surgeon</b>
Geneticist	On referral
Paediatrician	Dr. A.C. Bernard-Bonnin
Otolaryngologist	Dr. P. Arcand
Paediatric Dentist	Dr. C. Abelardo
Prosthodontist	Dr. C. Lamarche
Oral and Maxillofacial Surgeon	
Plastic Surgeons	Dr. L. Caouette Laberge, Dr. P. Bortoluzzi, Dr. P. Egerszegi
Orthodontists	Dr. H. El Khatib, Dr. B. Piquette, Dr. Gauthier
Dentist	
Speech Pathologists	N. Arsenault, A. Salois
Audiologist	On referral
Coordinators	S. Hernandez, D. Filiatrault
Social Worker	M. Roberge
Psychologist	D. Duchesne
Other	
Nurse Clinician	S. Santos

**Clinic Contact Information:**

**Address:** Cleft Palate Clinic  
 Hôpital Sainte-Justine  
 3175 Côte-Sainte-Catherine  
 Montréal QC H3T 1C5  
**Tel.:** 514-345-4931 (ext. 4759)  
**Fax:**  
**E-mail:** [lucie.thibault.hsj@ssss.gouv.qc.ca](mailto:lucie.thibault.hsj@ssss.gouv.qc.ca)

### 3. CHUQ Orofacial Malformation Committee (Maxillofacial and Cleft Lip/Palate clinic)

The team's clinic is held each month (10 clinics per year), with representation from all disciplines, in order to assess new patients, determine the necessity of bone grafts in four- to five-year-old patients with maxillary clefts and assess the orofacial condition of seven-year-old patients with orofacial malformations and syndromic cleft palate. The committee examines between five and seven patients over the course of a workday. Individual meetings are held in the morning with the paediatrician, the social worker, the speech pathologist and the maxillofacial surgeon, and the other team members meet with the patients together in the afternoon before having multidisciplinary discussion and establishing a treatment plan.

The parents are referred to the cleft palate clinic coordinator once the pre-natal diagnosis has been made. Then the parents meet with the geneticist and can, if they wish, meet with the ENT surgeon (who will close the cleft), the coordinator and the social worker. Once the baby is born, it can be transferred to the neonatal unit at the CHUQ Centre mère-enfant (Mother-Child Centre) if necessary. The team will take on the case once the baby has been hospitalized. A few days or weeks after birth, the child is assessed on an outpatient basis by the cleft palate team (see the earlier description of the workday). The team then establishes a treatment plan, which is explained to the parents by one or two members and transmitted to them in writing. Other appointments are scheduled with the whole team or individual members as needed. The team currently provides care to 434 active patients.

The sequence of clinical and surgical interventions for children with cleft lip and palate is generally as follows:

*Shortly after birth:* Telephone call to referring physician and parents. Insertion of palatal obturator plate if necessary. Auditory screening. Assessment of drinking skills by speech pathologist.

*1-2 months:* Child assessed by all team members if assessment not done in the hospital. Ear follow-up two months after palate surgery.

*3 months:* Lip surgery, preoperative examination in paediatrics. Postoperative ENT assessment.

*10-12 months:* Palate closed. Postoperative ENT, audiology and speech therapy assessment. Dental assessment.

*2, 3 and 4 years:* ENT and speech therapy follow-up. Audiology assessment at two years. Dental re-assessment at three years.

*Before child enters school:* Team reviews need for bone grafting, repair of oronasal fistula, or speech therapy if there are resonance disorders.

*7-10 years:* Orthodontic assessment, palatal expansion, bone graft as needed. ENT and speech therapy follow-up for resonance disorders as needed. Team re-assessment for clients as needed.

*End of growth:* Orthognatic surgery, lip and nose retouching, prosthodontics as needed.

<b>CHUQ Orofacial Malformation Committee</b>	
<b>Maxillofacial and Cleft Lip/Palate Team</b>	
<b>Team Leader</b>	<b>Dr. Jacques Leclerc, ENT Surgeon</b>
Geneticists	On referral: Dr. Maranda and Dr. Laframboise
Paediatricians	Dr. Claire Hudon, Dr. Julie Lessard
Otolaryngologists	Dr. Jacques Leclerc, Dr. Yolène Lacroix
Paediatric Dentist	Dr. Suzanne Hébert
Prosthodontist	Dr. Mary-Lou Landry
Maxillofacial Surgeons	Dr. Robert Paquin, Dr. Annie-Claude Valcourt
Plastic Surgeon	
Orthodontists	Dr. André Fournier, Dr. Isabelle Baillargeon
Oral Surgeon	Dr. Denis Binet
Speech Pathologists	Kati Abel, Élisabeth-Maude McConnell, Sophie Lacour
Audiologist	Joëlle Bélanger and audiology team at CHUL
Coordinator	Jocelyne Lévesque
Social Worker	Catherine Magnan
Psychologist	On referral
Other	
Administrative Officer	Sylvie Leprohon

**Clinic Contact Information:**

Address: CHUQ Orofacial Malformation Committee  
2705 Laurier Boulevard, Room S-9852  
Sainte-Foy QC G1V 4G2

Tel.: 418-525-4444, ext. 47694

Fax: 418-654-2280

E-mail: [jocelyne.levesque@chuq.qc.ca](mailto:jocelyne.levesque@chuq.qc.ca)

## **The Adult Patient**

The three Quebec clinics treat patients with orofacial clefts up to the age of 18, when they are discharged. In cases where treatment is still in progress, patients will be treated for longer. Sometimes hearing, speech and dental problems persist into adulthood, and patients must then seek treatment outside of the cleft palate clinics. Adult dental care is not insured and the patient must cover all costs.

## **Speech language pathology**

Children are treated by the cleft palate team's speech pathologist from birth (for the CHUQ team) or from the age of two up to the age of 18 for speech monitoring (articulation, resonance) if necessary. Children living in remote areas can also receive speech therapy in their community with support from the speech pathologist on the specialized team. These services are covered under provincial health insurance. If the child has delayed language or speech development or swallowing issues that are not related to the cleft or orofacial malformation, follow-up will be done in the health network and education sectors (health and social services centres, physical disability rehabilitation centres, schools). The team speech pathologists can schedule follow-up appointments for the child for related issues to the cleft or orofacial malformation. With regard to language follow-up (oral and written), there is a waiting period in the health and education sectors for speech therapy services, and many parents who have the means opt for additional private appointments.

## **Medical Travel Assistance**

Health and social services centres (CSSS) provide some financial aid to cover the cost of medical travel by patients living in remote areas. The amount of aid varies from region to region. Families may also receive financial aid for accommodation or accommodation at a reduced rate.



## New Brunswick

Atlantic Canada's birth rate, and in particular New Brunswick's, lags behind the rest of Canada. According to statistics Canada, the number of births in New Brunswick stayed relatively constant from 2003 to 2008 at approximately 7000 births per year (20). The birth rate suggests that over the same period the province should have received, more or less, seven newborn CL/P and five CP cases annually.

The only Cleft Lip and Palate Clinic in New Brunswick operates out of the Saint John Regional Hospital. The clinic has been running since prior to 1973 and is located at the paediatric ward. There had been a cleft palate team at one time at the Dr Everett Chalmers Hospital, in Fredericton, however that team is no longer in existence. As a result, oral cleft cases from the northern parts of the province are referred to the cleft palate team in Saint John or to one of the clinics in Quebec. Similarly, cases from the Moncton area and the Eastern part of the province are referred to either the clinic in Saint John or to the IWK centre, in Halifax. Children with complex craniofacial conditions are referred to Halifax, Montreal or Toronto, and are followed up in Saint John. There is no provincial registry for oral cleft patients, so it is uncertain just how many patients obtain treatment outside the province. The Saint John Regional Hospital clinic maintains a clinic registry of all patients. The number of new and newborn patients registered in recent years are provided in Table 17.

**Table 17. Saint John Regional Hospital Cleft Palate Clinic Registration 2005-2009**

YEAR	Patients Registered	Newborn Patients
2009 (as of June)	2	1
2008	4	3
2007	3	0
2006	7	4
2005	6	3

## New Brunswick Cleft Palate Program

The New Brunswick Cleft Palate Program is funded by the Department of Health and Wellness, and administered by Medavie – Blue Cross. The program provides financial assistance for dental treatment to families of children (0-18 years) born with a cleft of the hard palate.

**Eligibility:** Acceptance into the program is based on a family’s financial information, as disclosed on the government application form, which can be obtained from Medavie-Blue Cross. As such, approval or denial into the program is not adjudicated by a dental consultation board, but rather an eligibility calculation that takes into account total family income after deductions, number of dependants in the family and annual cost of the dental treatment. If the result of the calculation is below the indicated threshold amount, the child is accepted into the program and 100% of the general practitioner or specialist fee guide cost of the dental treatment will be covered. On the other hand, if the eligibility calculation results in a sum that is above the threshold amount, the child is refused from the program and none of the cost of dental treatment is paid. The threshold amount is reviewed annually and currently stands at \$34,749. A new application form must be completed for each phase of treatment, as the family’s financial status must be re-evaluated at each phase. The program is the payer of last resort.

**Services:** Dental treatment covered under the program is separated into three phases:

1. Initial Treatment – involves services such as consultation, feeding appliance, obturator and orthodontic records (which includes examinations, radiographs and treatment planning);
2. Orthodontic – including braces as well as appliances which may be required prior to braces; and
3. Prosthodontic – work that may be required to replace missing teeth, including dental implants.

**Service Provision:** Treatment must be provided by a dental specialist

**Utilization and Expenditures:** The New Brunswick Cleft Palate program dental treatment utilization and expenditures are provided in Table 18.

**Table 18. New Brunswick Cleft Palate Program expenditures and utilization**

Year	Number of Discrete Patients	Phase 1 Expenditures	Phase 2 Expenditures	Phase 3 Expenditures	Total Expenditures
2008	22	\$3,949	\$25,917	\$35,144	\$65,010
2007	20	\$962	\$26,882	\$24,825	\$52,669
2006	23	\$2719	\$21,468	\$2,226	\$22,413

### **Saint John Regional Hospital Cleft Palate Clinic**

The team clinic is held eight times per year (four clinics in the Spring and four clinics in the Fall), on Friday mornings. During a session, an average of twelve patients will be seen by the oral surgeon, plastic surgeon, orthodontist, SLP, audiologist, paediatrician, otolaryngologist and photographer. Following assessment by the entire team a treatment plan and follow-up schedule is determined. At the present time the team is actively following 61 patients.

The regional health authority does not offer any additional budgetary funding towards the operation of the cleft palate clinic; however, the professionals that make up the team continue to sustain the clinic and provide multidiscipline care in the hospital or in their private practice. The members of the team either work for the Health Authority or are hired on as consultants on a fee-for-service basis. The team does not have a full-time dedicated coordinator. Instead, the clinic and patient documents are maintained by the Department of Paediatrics administrative assistant and two ward clerks, as a secondary duty. These individuals are also responsible for coordinating appointments with the specialists.

<b>Saint John Regional Hospital Cleft Palate Clinic</b>	
<b>Team leader</b>	<b>Dr. Emile Paras (Paediatrician)</b>
Geneticist	Travelling Genetics Clinic or referral to IWK
Prenatalist	Dr. Frank Sanderson, Dr Donald Colford
Paediatrician	Dr. Emile Paras
Otolaryngologist	Dr. David Tees
Paediatric Dentist	
Prosthodontist	
Oral Surgeon	Dr. Jeff Watson
Plastic Surgeon	Dr. Don Lalonde
Orthodontist	Dr. Don Fitzpatrick
Dentist	
Speech pathologist	On rotation
Audiologist	On rotation
Nurse Coordinator	Kim Aker, Sheryl Pazia
Social Worker	Stefan Mildemberger
Psychologist	Monica Green-Nissen, Robin Patterson
Other	Charlene Ross (Secretary Department of Pediatrics)
Administrator	

**Clinic Contact Information:**

Address: Cleft Palate Clinic  
 Department of Pediatrics, Clinic 2, Level 1  
 PO Box 5200  
 Saint John, NB, E2L 4L4

Tel: 506-648-6811  
 Fax: 506-648-7217  
 Email: [emileparas@hotmail.com](mailto:emileparas@hotmail.com)

**The Adult Patient**

The Saint John Regional Hospital Cleft Palate Clinic will follow patients until the age of 18 and perhaps even longer, if required. Once patients are discharged they can still be seen by specialists for medical and dental services, but not with the same multidiscipline team approach. In order to be eligible for dental benefits under the Cleft Palate Program, treatment must be initiated prior to December 31<sup>st</sup> of the year in which the patient turned 18 years of age. If this condition is satisfied, the patient will be eligible until the course of treatment has been completed.

## Nova Scotia

The largest cleft palate and craniofacial clinic in Atlantic Canada has been operating at the Isaac Walton Killiam (IWK) Health Sciences Centre, in Halifax, since 1972. The clinic currently treats approximately 625 active patients. All Nova Scotia patients with cleft lip and/or palate or other craniofacial anomalies are cared for by the team at IWK. Patients are received immediately following birth, as referrals from other practitioners at any age, transfers from other provinces, as well as new Canadian citizens arriving from abroad. In addition, the team receives many referrals from New Brunswick and nearly all referrals from PEI. The IWK clinic keeps a registry of all patients. Nova Scotia residents are further registered under the provincial Medical Services Insurance Cleft Palate/Craniofacial Program in order to be eligible for insured dental services. The numbers of new and newborn patients registered at IWK, in recent years, are provided in Table 19.

**Table 19. IWK Clinic Registration 2005-2009 – Patients with Cleft Lip and/or Palate**

<b>YEAR</b>	<b>Patients Registered</b>	<b>Newborn Patients</b>
2009 (as of June)	27	16
2008	42	27
2007	40	28
2006	35	24
2005	34	20

## Nova Scotia Cleft Lip and Palate Dental Benefit Programs

The government of Nova Scotia offers eight public dental programs; seven of which fall under the authority of the Department of Health. The department of Health provides policy, direction and funding, while Medical Services Insurance (MSI) administers the programs. Adjudication and payment is contracted by Quikcard Solutions Inc. (QSI). A Dental Fee Tariff has been negotiated between the Department of Health and the Nova Scotia Dental Association. QSI will pay up to the negotiated tariff cost per payment code; dental care providers are not permitted to bill any difference between the clinic fee and negotiated fee tariff. Patients with private dental plans are required to access their private coverage first; the programs compensate for any remaining balance. As a result, entitled patients under any program receive 100% coverage for eligible dental treatment.

Patients with oral clefts typically receive most of their dental treatment benefits from three plans. From birth to age 10 all children in Nova Scotia are insured for basic dental services under the Children's Oral Health Program (COHP). The Cleft Palate/Craniofacial Program covers additional dental services, not covered under the COHP, until 23 years of age. Palatal obturators and feeding appliances are covered under the Maxillofacial Prosthodontic Program.

## 1. Children’s Oral Health Program (COHP)

**Eligibility:** This program is available to all children from birth and until the end of the month in which the child turns ten years of age. No registration procedures are required.

**Services:** A range of diagnostic, preventive and treatment services.

**Service Provision:** Dentists, dental hygienists and dental assistants in private and community clinics.

**Utilization and Expenditures:** Annual expenditures under this program are almost 4 million dollars.

## 2. Cleft Palate/Craniofacial Program

**Eligibility:** Registered patients who have a craniofacial anomaly that directly influences the growth and development of the dentoalveolar and craniofacial structure. The program does not limit coverage only to clefts of the hard and soft palates, lip and/or alveolus, but also provides coverage for other dental anomalies and syndrome conditions. In order to be registered for the program, patients have to be seen by the Cleft Palate /Craniofacial Team at IWK and followed according to Team principles. Eligible patients are entitled to services provided under the program from birth to the end of the month in which they turn 23.

**Services:** Benefits covered under the program include orthodontic, diagnostic, restorative, periodontal and prosthetic treatment related to, though not necessarily restricted to the area of the cleft deformity. Surgical procedures, such as dental implants, are also provided under this program.

**Service Provision:** The provision of dental treatment is not limited to the IWK CPT; it is also open to dentists and specialists in private practice. At their discretion, MSI will submit any or all treatment plans for review to an IWK cleft palate team committee, which includes dental specialists and government representatives, prior to approving or denying treatment coverage. This is most often the case for costly and complex prosthodontic treatment requiring dental implants. In some cases, and on an independent basis, a non- predetermined cap may be placed on total treatment coverage under the plan.

**Utilization and Expenditures:** Utilization and expenditures under the Program are provided in Table 20.

**Table 20. Cleft Palate/Craniofacial Program expenditure and utilization.**

YEAR	NUMBER OF PATIENTS SEEKING BENEFITS	NUMBER OF CLAIMS	TOTAL COST
2008	210	1022	\$97,951.62
2007	219	1010	\$90,978.33
2006	213	920	\$101,510.84

### **3. Maxillofacial Prosthodontic Program**

**Eligibility:** Registered patients whose maxillofacial prosthodontic needs have been the result of congenital facial disorders, cancer, surgery, trauma, and neurological deficit. Patients are registered with QSI/MSI under the program after the approval of their first claim submission. There are no age restrictions under this program.

**Services:** A range of dental services required to meet the functional needs of patients in order to permit adequate speech, mastication and swallowing. For oral cleft patients the fabrication and relining of prosthetic palatal obturators and feeding appliances are funded by this program.

**Service Provision:** The provision of services is limited to three providers possessing specialist qualifications in this area.

**Utilization and Expenditures:** Annual expenditures under this program are \$600,000. Obturators and feeding appliances for cleft palate patients make up a very small fraction of the total payments.

### **Isaac Walton Killiam Health Sciences Centre Cleft Palate / Craniofacial Clinic**

The team clinic is held on a weekly basis, almost every Thursday morning, resulting in approximately 45 clinic days per year. Every team clinic is followed by a clinical care team meeting to discuss each patient's case individually and to outline a treatment plan. Core members of the team include an audiologist, otolaryngologist, dentist, nurse, paediatrician, plastic surgeon, orthodontist, oral maxillofacial surgeon and a speech-language pathologist. Patients are followed in the outpatient clinic by the entire team or specific specialists, as per their requirements. Referrals to Genetics, Psychology, Diagnostic Imaging are also coordinated when necessary.

A summary of services and patient educational materials is available on the hospital website: <http://www.iwk.nshealth.ca/index.cfm?objectid=329D6A94-B054-23CF-36682276E67CCB3E>.

<b>IWK Cleft Palate/Craniofacial Team</b>	
<b>Team leader</b>	<b>Dr. Kathy Russell, orthodontist</b>
Geneticist	
Prenatalist	
Paediatrician	Dr. Eva Sudek
Ear Nose Throat	Drs. Charlie Cron, Gerard Corsten
Paediatric dentist	Drs. R. Anderson, T. Doyle, J. MacLellan, H. Dymment
Prosthodontist	Dr. Stuart Richardson
Oral Surgeon	Dr. David Precious
Plastic Surgeon	Dr. Ken Wilson
Orthodontist	Dr. Kathy Russell
Dentist	
Speech pathologist	Cindy Dobbelsteyn
Audiologist	Michel Comeau
Nurse Coordinator	Gerry Half-Penny Franklin (Nurse Clinician) Linda Huntley (Nurse Co-ordinator)
Social Worker	On referral
Psychologist	On referral
Other	Farris MacPherson (Family representative)
Administrator	Linda Huntley

**Clinic Contact Information:**

Address: IWK Health Centre  
5850 University Ave.  
Halifax, NS, B3J 3G9

Tel: 902-470-8027  
Fax: 902-470-8137  
Email: [kathy.russell@dal.ca](mailto:kathy.russell@dal.ca)



## **The Adult Patient**

Patients are routinely followed up to the age of 18, but may continue to be seen up to the age of 23 if needed. Adult patients that require follow-up by only one or two clinicians, and not the entire team, will be seen in the clinicians' private offices. Normally dental treatment under the Cleft Palate / Craniofacial program is not covered for patients older than 23; however, under extenuating circumstances where the cleft palate team has concluded that the condition requiring retreatment is due to the progression of the congenital anomaly, and not neglect, patients older than 23 years of age can be approved for further treatment.

The IWK team will also examine adult patients with craniofacial anomalies and arrange appropriate referrals. A patient who is older than 23 years of age but has never received previous dental treatment for a congenital cleft palate or other craniofacial anomaly can receive special consideration for dental benefits under the Cleft Palate/Craniofacial Program.

## **Speech-Language Pathology**

Speech-Language Pathology consultative services for children born with cleft lip and/or palate are provided within the Cleft Palate Clinic at the IWK, and are funded by the Nova Scotia Department of Health through the Nova Scotia Hearing and Speech Centres (NSHSC). Treatment services for preschoolers are also provided and funded through the NSHSC throughout the province. School-aged children are served within the school system, funded through the individual school boards, or privately. In situations where a child attends private school or is home-schooled the child would have to seek out private services, which can be costly. Private Health plans provide limited coverage. Many families elect private therapy to supplement what they are able to get publicly, because public services are often insufficient. Following high school completion, services are again available and funded through NSHSC with no age restriction.

## **Medical Travel Assistance**

Lodging for overnight hospital stays are arranged by the admittance department at a low cost. Alternatively, families are welcome to room in the child's hospital room during their admission. Families book their own accommodations for CLP clinic visits. Some hotel and lodges offer discount hospital rates.

## Prince Edward Island

From 1993 to 2002 oral clefting was identified in 29 infants in Prince Edward Island (PEI), for a rate of 1.84/1000 total births (31). Prince Edward Island's birth rate is the highest of all Atlantic Provinces, however as the smallest province by population, PEI has averaged 1375 births annually, over the past five years (20). This would suggest that the provincial health authority sees between one and three new CL/P and CP cases every year, a number which is too low to sustain a comprehensive cleft palate team. As such, patients with oral clefts are referred for follow-up and care to the Cleft Palate and Craniofacial clinic at IWK, in Halifax. An Out-of-Province Liaison program is in place to assist families with coordination of medical services in Halifax and PEI.

PEI residents with cleft palate can receive subsidized dental treatment benefits from two separate programs administered by PEI Dental Public Health - Children's Dental Care Program (CDCP) and the Cleft Palate Orthodontic Treatment Funding Program. A description of the two dental programs is provided.

### 1. Children's Dental Care Program (CDCP)

The CDCP provides preventive and basic dental services to eligible children. Preventive services are provided in schools and public health clinics by dental public health staff. Participation in the preventive program is free and available, without registration, to all children aged 3 to 17 years. To receive basic dental treatment (diagnostic, restorations, and extractions) under the CDCP, families pay a \$15 per year registration fee for each child, up to a maximum of \$35 for all the children in the family. In 2004, the CDCP introduced a 20% co-pay on treatment services. Families that earn less than \$30,000 per year after taxes are exempt from paying the co-payment.

**Eligibility:** All children between the ages of 3 and 17 that are residents of PEI and have a Medicare Personal Health Number can register for the program.

**Services:** A range of diagnostic and treatment services including examinations, radiographs, fillings, extractions and root canals (on anterior teeth).

**Service Provision:** Dentists provide treatment in private practice and dental public health clinics. Dental hygienists and dental assistants provide preventive services and prophylaxis in school clinics and Dental Public Health clinics.

### 2. Cleft Palate Orthodontic Treatment Funding Program

In 1996, the Cleft Palate Orthodontic Treatment Funding Program was introduced in order to partially cover the cost of necessary orthodontic treatment when the orthodontic problem is directly attributed to a cleft palate. This program is very similar to the New Brunswick Cleft Palate Program in that it is broken down into three stages of treatment and utilizes a family income calculation at each stage. The expenses for each stage of treatment are cost shared between the parents and Dental Public Health.

No less than 50% of eligible treatment (to a maximum of \$2,500) is covered by Dental Public Health. In addition, parents can further apply for further financial assistance of 75% (to a maximum of \$3,750) and 100% (up to a maximum of \$5,000). Approval for additional assistance is dependent on a family's income and size in accordance with the following financial assistance scheme:

100% funding - If the annual household income is less than in Column A for the corresponding family size.

75% funding - If the annual household income falls between Column A and Column B for the corresponding family size.

50% funding - If the annual household income is greater than in Column B for the corresponding family size.

Family Size	Column A	Column B
2	\$22,000	\$34,000
3	\$26,000	\$38,000
4	\$32,000	\$44,000
5	\$38,000	\$46,000
6	\$42,000	\$46,000

An application form completed jointly by the parents and the paediatric dentist (or orthodontist) is submitted to Dental public Health prior to each stage of treatment. Once received, the application is reviewed by a committee of dentists and representatives of child and family services in order to determine eligibility and level of funding under the program.

**Eligibility:** All patients under the age of 17, who are registered with a cleft palate clinic and have crooked teeth related to a hard tissue cleft palate. Treatment benefits are cost shared and depend on family income and size. The program is the payer of last resort.

**Services:** The program is divided into the following three stages:

- a. Early Stage – Provides coverage for an obturator or feeding appliance that may be required at infancy.
- b. Intermediate Stage – Provides coverage for dental arch expansion, at six to eight years of age, but only if bone grafting is also necessary.
- c. Final Stage – Provides coverage for comprehensive orthodontic treatment. Treatment must commence prior to the seventeenth birthday.

**Service Provision:** Treatment must be provided by either a paediatric dentist or orthodontist.

**Utilization and Expenditures:** Since the program was created in 1996, 53 patients have been registered for dental benefits under the program at a total overall cost \$73,445.82. Program expenditures in recent years are presented Table 21.

**Table 21. Cleft Palate Orthodontic Treatment Funding Program expenditures.**

YEAR	TOTAL EXPENDITURES
2008	\$6,117.00
2007	\$7,085.46
2006	\$7,547.43
Since inception 1996 -2008	\$73,445.82 (53 cases)

## **Medical Travel Assistance**

The province does not provide any travel financial assistance for patients and parents that report to the IWK. Travel expenses can be claimed on a family's income tax submission. When a patient is scheduled for surgery at the IWK, there are provisions for lodging and meals under PEI Medicare, following approval through the Out-of Province Liaison Program. In addition, once a child is admitted for surgery parents are allowed to room with the child at the hospital. Alternatively the Out-of - Province Liaison can suggest affordable family accommodations, including the local Ronald McDonald House, which are available at the family's expense.

### **Contact Information:**

PEI Liaison Office  
QEII Health Sciences Centre  
1278 Tower Road, Bethune Building  
Halifax, Nova Scotia, B3H 2Y9

Tel: 902-473-7398

Fax: 902-473-2191

## Newfoundland and Labrador

The only cleft palate and craniofacial centre in Newfoundland and Labrador operates out of the Janeway Children's Health and Rehabilitation Centre, in St John's. The program was started in 1975 and is the province's primary care source for patients with cleft lip and palate and other craniofacial conditions. For patients residing outside the St. John's area, travel to the clinic and access to orthodontic services, can be difficult. Four out of the province's five orthodontists work in St. John's. One orthodontist works out of Corner Brook but also travels to treat patients in more remote areas. The province's Medical Transportation Assistance Program provides some financial funding for patients and escorts that need to travel a distance greater than 200km for medical treatment.

There is no provincial registry for patients with oral clefts; however the clinic at the Janeway maintains a database of patients. There are currently 215 active patients being followed by the team. Newborn patient registrations are provided in Table 22.

**Table 22. Janeway Children's Health and Rehabilitation Centre New Patient Registration 2005-2009**

<b>YEAR</b>	<b>Patients Registered</b>	<b>Newborn Patients</b>
2009 (as of July)	N/A	12
2008	N/A	3
2007	N/A	11
2006	N/A	7
2005	N/A	9

## Newfoundland and Labrador Dental Programs for Patients with Cleft Lip and Palate

The Department of Health and Community Services funds the provincial Dental Health Plan (DHP), which is administered through the province's Medical Care Plan (MCP). The DHP encompasses a number of dental programs, including the Children's Dental Program (CDP). A Dental Monitoring Committee adjudicates over the eligibility of dental treatment coverage for severe conditions affecting the dentition that fall outside the parameters of the DHP. Examples include maxillary clefts of the hard tissues. This is done on a case by case basis. The Dental Monitoring Committee is made up of two non-voting members (Director Dental Services and Financial Claims Manager) and three paid voting members from the dental profession. The Dental Monitoring Committee meets at least four times per year to review dental treatment plans. If a dental treatment plan for cleft palate patients is approved dental costs are covered at 100% and MCP becomes the payer of last resort.

## 1. Children’s Dental Program

**Eligibility:** This program is available to all children from birth until the age of 12.

**Services:** A range of diagnostic, preventive and treatment services in accordance with the MCP payment schedule. Providers are not allowed to balance bill for services covered under the program. MCP is the payer of last resort.

**Service Provision:** Dentists, dental hygienists and dental assistants in private practice and community clinics.

## 2. Dental Monitoring Committee Adjudication of Cleft Palate Cases

**Eligibility:** The Dental Monitoring Committee deems it appropriate to authorize coverage under the DHP for dental procedures that are essential to the treatment of maxillary clefts of hard tissue. There are no age restrictions for initiation of treatment.

**Services:** All services directly related to the repair, treatment and restoration are assessed; the coverage for dental implants is restricted. Once a treatment plan is approved, the DHP is the payer of last resort for the cost of any orthodontic, restorative, periodontic, surgical and prosthodontic services.

**Service Provision:** Providers can be either General dentists and/or dental specialists, who have been granted approval of payment, following the submission of a detailed treatment plan and records to the Dental Monitoring Committee.

**Utilization and Expenditures:** The exact annual expenditures specifically for the treatment of cleft palate under the DHP shows annual fluctuations. Approximate expenditures, on an annual basis, are represented in Table 23.

**Table 23. Approximate Expenditures under the DHP for Cleft Lip and Palate care**

Services	Estimated Annual Cost
Prosthodontics (cases completed)	\$10,000 (4 cases)
Orthodontics (cases ongoing)	\$103,000 (20 cases)

## **Janeway Children's Health Cleft Palate/Craniofacial Clinic**

The team clinic is held monthly on the first Wednesday of every month, between 08h30 and 12h00. On average, ten patients are seen during the session. Present at the clinic are the pediatrician, otolaryngologist, plastic surgeon, SLP, nurse coordinator, social worker, psychologist, dental hygienist. The paediatric dentist is available in the hospital and sees patients for consultation if required. Patients are referred to the orthodontist's office, in St John's, for consultation. On occasion, an out of province oral maxillofacial surgeon will be available to see patients on referral. The nurse coordinator receives referrals prenatally and arranges to meet with and provide information to the families. When a child with an oral cleft is born the nurse coordinator is again the first team member to be summoned in order to coordinate clinic visits and follow-up appointments. Most newborns will also be seen by some of the team members during the hospital stay.

In the past, infants with oral clefts born in remote areas of Newfoundland and Labrador were immediately air-lifted to Janeway at birth, primarily due to a lack in the understanding of how the infants should be handled by the community healthcare providers. This would at times result in the child being unnecessarily separated from the mother for an extended period of time. A new initiative, funded by a provincial grant, is currently underway to bring resources to remote areas and to educate community healthcare workers with regards to how infants with oral clefts should be handled and fed, what conditions should necessitate immediate air lift to Janeway, and what conditions can await transportation until the mother and infant are ready to travel.

<b>Janeway Children's Health Cleft Palate/Craniofacial Team</b>	
<b>Team leader</b>	<b>Dr. Sue Moore (Paediatrician)</b>
Geneticist	Mary Connolly-Wilson
Prenatalist	
Paediatrician	Dr. Sue Moore
Ear Nose Throat	Dr. Wayne Redmond
Paediatric dentist	Dr. Geoff Smith
Prosthodontist	
Oral Surgeon	
Plastic Surgeon	Dr. David Jewer, Dr. Art Rideout, Dr. Donald Fitzpatrick
Orthodontist	Dr. James Flynn, Dr. Christa Oliver
Dentist	
Speech pathologist	Dawn Dodge
Audiologist	
Nurse Coordinator	Suzanne Dyke
Social Worker	Debbie Callahan
Psychologist	Janine Hubbard
Other	Anne Clift (Dental Hygienist), Ward Kinsella (Social Work Assistant), Sandy Delaney (Occupational Therapist), Sarah Chapman (Dietitian)
Administrator	

**Clinic Contact Information:**

Address: Janeway Children's Health and Rehabilitation Centre  
300 Prince Philip Drive  
Saint John's, NL, A1B 3V6

Tel: 709-777-4005 or 709-777-4661

Fax:

Email: [suzanne.dyke@easternhealth.ca](mailto:suzanne.dyke@easternhealth.ca)



## **Adult Dental Treatment**

The cleft palate clinic at the Janeway follows children up until the age of 18. If their treatment is incomplete by the time they turn 18, they are referred to plastic surgeons, otolaryngologists and orthodontists that will continue to monitor and treat these young adults, as necessary.

There is no age restriction for dental coverage under the DHP. Patients are encouraged to share responsibility for the maintenance of insured dental treatment. Coverage for the duplication and repair of previously completed dental services is restricted and will take into account the patient's contribution to his or her oral health. Extension of additional coverage is at the discretion of the Dental Monitoring Committee.

## **Speech Language Pathology**

Children who are referred to the Cleft Palate and Craniofacial Clinic are screened and monitored by the team's SLP approximately once a year, and more often if necessary. If warranted, a full assessment is completed, including articulation evaluation, nasometry and videofluoroscopy. If the child is preschool aged and lives in the St John's area, the child will be followed by the team SLP for therapy if deemed appropriate. Alternatively, there are 11 hospitals outside the St. John's region that have SLP services which the preschoolers can access. As is the case in many provinces, the waiting list to receive therapy can at times be long. School-aged children are seen by the SLP that is assigned to their school. Most schools in the public system have an assigned SLP, but wait times again vary depending on a variety of factors.

## **Medical Transportation Assistance Program**

Recognizing that specialized health services in the province are centered in St John's and that travel for medical services can be a financial burden on patients and their families, the Department of Health and Community Services provides some financial assistance for medical travel under the Medical Transportation Assistance Program (MTAP). This Program is available to residents of Newfoundland and Labrador who must travel a distance greater than 200km by air or by bus in order to access medically necessary insured services. The Program operates on a partial assistance/partial pay basis, whereby the program funds a portion of the cost for travel, accommodations and meals for patients and escorts, and the family pays the other portion. The amount of assistance will vary depending if the point of travel originates in Labrador or on the island and whether the destination is within or out of province. The MTAP is the payer of last resort; therefore, funding of expenses under the program will be reduced by the amount paid by the private insurance plan prior to assessment under the MTAP. Since dental treatment, including orthodontic services, for cleft palate patients are considered insured services under MSP, families are able to access benefits under the MTAP when they must travel to receive follow-up care at the cleft palate clinic or from the orthodontist.

## Yukon, Nunavut, and Northwest Territories

There are no cleft palate teams operating in the North. Patients with oral clefts are normally referred to the cleft palate teams in Vancouver, Edmonton, Winnipeg and Ottawa. The frequent travel can be especially hard on an infant and the family in the first year following birth when several meetings with a cleft palate team are necessary. For example, a newborn with a cleft lip and palate from Yellowknife will be transferred to Edmonton shortly following birth for observation and assessment, then at three months for lip surgery and again at 6 months for audiology and SLP assessment. At 12 months the palatal surgery is performed followed by another audiology and SLP assessment at 16 months.

The Yukon, Nunavut and the Northwest territories have similar dental benefit plans for CLP patients. More than half of the population in the North is covered under NIHB. Individuals that are not already covered for dental benefits through a federal and territorial act or by private or group insurance, are able to receive dental coverage for the treatment of cleft palate and other craniofacial conditions, through each of the respective Territorial Health and Social Services Departments. Yukon residents who have a chronic disease or a serious functional disability are able to access coverage through the Chronic Disease and Disability Benefits Program (32). Residents of the Northwest Territories are able to access the Extended Health Benefits Program (33). In Nunavut, coverage for treatment and travel is available through the Territories broad range of Health and Social Services Programs. All of the Territories provide dental benefits for CLP patients that are comparable to the dental benefits provided under NIHB. Similarly, the programs also include provisions for the cost of travel, lodging and meals.

In Edmonton, there is a team of six health care professionals, including three registered nurses that work for Capital Health's Northern Health Services Network (NHSN). They will assist patients and their families from the Northwest Territories, Nunavut and the Yukon by coordinating care, discharge planning and follow up services at Alberta Health Services – Capital Health Sites.

Northern Health Services Network (NHSN)  
Room 570, Community Services Centre  
Royal Alexandra Hospital  
10240 Kingsway Avenue  
Edmonton, Alberta  
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Telephone: 780-735-5761  
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