you & your baby

Newborns with Cleft Lip & Palate

A Resource for Health Care Professionals and Families

Eastern Health
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September 2009
Acknowledgements

The Janeway Cleft Lip, Palate and Craniofacial Team
wishes to gratefully acknowledge:

We also thank the parents for supporting this project by
freely sharing the many photos you see in this binder.

Without their generous support and contributions this
binder would not be possible.

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Anne Clift, Dental Manager, Janeway - (left)
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Congratulations on your new arrival and welcome to the team!

We are the Janeway Cleft Lip, Palate and Craniofacial Team. As a parent you will become an important part of our team but the most important person right now is your new baby.

Your first contact with the team and your “go to” person is the nurse coordinator. She keeps in touch with the rest of us when we are needed. You can reach the nurse coordinator at 709-777-4661 or 709-777-4005.

Other members of the team include a pediatrician, plastic surgeon, Ear, Nose and Throat (ENT) specialist, pediatric dentist, dental hygienist, speech language pathologist, dietitian, occupational therapist, psychologist, social worker and geneticist.

Some of the individual team members will see you and your child more frequently, especially in the first year. There are also regularly scheduled clinic visits where you will see the whole team. These visits usually take place on the first Wednesday of each month.

We are looking forward to meeting you and your new little one in the near future.

Sincerely,
The Team
A Resource for Health Care Professionals and Families

The Janeway Cleft Lip, Palate and Craniofacial Team at Eastern Health is pleased to present this resource binder for health care professionals and families about newborns with Cleft Lip and Palate.

The team was inspired to pursue this project because of challenges encountered by health care staff and families when babies were born with cleft lip and palate.

It is important for families to know that a cleft in the lip or palate does not automatically indicate any other problems with the baby. Many babies born with clefts have no other health issues at all. Parents need to be reassured by receiving information from health care professionals about all the normal aspects of their baby’s exam and proper terminology to describe any abnormal findings. They also need to be told that the cleft is not painful. (Cleft Palate Craniofacial J. 2001 Jan;38 (1): 55-8)
On average, ten babies are born in Newfoundland and Labrador each year with this condition and the births occur throughout the province. Consequently many staff working in obstetrics have never taken care of a newborn with cleft lip and palate. Similarly community health nurses have little experience helping the family once the baby comes home.

**This resource will address two main issues:**

1. The primary issue is *feeding the baby.*
2. The second is *providing information* (mainly in the form of photographs) about expected treatment from birth until surgical repair is completed.

**Note for Health Care Professionals:**
Please note that Janeway Cleft Lip, Palate and Craniofacial Team at Eastern Health has agreements in place with agencies and foundations that provide us with *supplies for newborns with cleft lips and palates.*
For more information on how you can benefit, please view the [Resource & Contact Information](#) at the end of this binder.
Feeding

Feeding issues are the main reason a newborn with cleft lip and palate is transported to the Janeway Neonatal Unit immediately after birth. This practice deprives the family of time to bond with their new baby.

With better supports for feeding in the community, the newborn could go home with mom following a normal length of stay in the birthing hospital.

While the family does need to meet with the Cleft Lip, Palate and Craniofacial Team at the Janeway, that visit can be planned for a couple of weeks later when mom and baby are feeling better able to travel.

* Please view the Resource and Contact information at the end of this binder (page 33).
How do you feed your baby?

**Main Feeding Concern**
Newborns with a cleft often have difficulty sucking, mainly because they cannot easily create a vacuum to suck milk from the breast or bottle.

**Cleft Palate Bottle**
There is an infant feeding bottle especially designed to help with feeding called a *cleft palate bottle*. The bottle itself is flexible so you can help the baby feed, by squeezing milk from the bottle into their mouth.

You can get cleft palate bottles by calling the nurse coordinator in St. John’s, at (709) 777-4661 or (709) 777-4005. Please refer to resource and contact information at the end of this binder (page 33) for more information.
Breastfeeding

Breastfeeding a newborn with cleft palate is difficult because of the problems the infant has making a seal. With persistence one of our moms was able to breastfeed her baby. You may also express breast milk and feed it to your baby using the cleft palate bottle.

Feeding with Cleft Palate Bottle

Feeding your baby 2-3 oz. of milk should not take longer than 30 minutes. If it does, review how much expressed breast milk (EBM) or formula you are squeezing out by squeezing it into a cloth. Also consider how fast you are squeezing the bottle. Babies typically suck and swallow once every second. Make sure you do not flood your baby’s mouth with milk. Sometimes changing the flow rate of the nipple is helpful.
Prematurity and Cleft Lip and Palate

Sometimes babies born with cleft lip and palate are also premature – less than 37 weeks gestational age. The combination of these two issues can contribute to feeding difficulties. Assessment by a feeding specialist (occupational therapist, speech language pathologist) is recommended.
Because babies with clefts often have trouble feeding, it is important to monitor weight to ensure they are receiving enough nutrition to support normal growth and development. It is normal for the baby to lose weight in the first week of life and each baby gains at his or her own rate; but by two weeks of age, weight should be back to the birth weight.

It is recommended to have the baby weighed every 1-2 weeks on the same scales for the first month or two. If the baby is premature more frequent growth monitoring may be needed.

**Growth and Development**

If the newborn cannot tolerate the volume necessary to maintain growth and development, or it takes too long per feeding, the number of calories per ounce can be increased. For example, EBM or regular infant formula has 20 calories per ounce, but expressed breast milk or formula can be mixed to give 24 and even 27 calories per ounce. *This should only be done with the guidance of a dietitian.*
Extra Testing
Cleft lip and/or palate is usually an isolated birth defect, however, occasionally cleft lip and/or palate can be seen in conjunction with other anomalies or may occur as part of a genetic syndrome or chromosomal abnormally. Therefore a cranial and renal ultrasound are recommended to screen for the possibility of other abnormalities.

Pierre Robin Sequence
Sometimes babies born with cleft palate also have an associated condition called Pierre Robin Sequence. In addition to the cleft palate these babies also have a small lower jaw relative to the size of the face, and the chin can appear retracted (set back). Babies born with Pierre Robin Sequence can have difficulty sucking because of the small lower jaw and cleft palate. As the baby grows the lower jaw tends to catch up. Some of these babies may have breathing difficulties related to airway obstructions from the tongue falling back and blocking the airway. These problems can be decreased with repositioning. As children with Pierre Robin Sequence grow, issues related to feeding and breathing improve.
Families understandably have many questions about the surgery and especially want to see pictures of children who have had their cleft surgically closed.

At the end of this resource binder, you’ll find some excellent websites that families can check out when they get home, because during the hospital stay, there may be limited access to the internet.

Prior to development of this resource many families waited until they came to the Janeway to see pictures. In order to provide this information to families right away, we have included photos of children with cleft lip and palate from birth until post surgery.

**Surgery to correct cleft lip and palate**

The two main surgeries for babies born with cleft lip and palate are **lip repair** which is done at three to six months and **palate repair**, which is done at about 12 months. The plastic surgeon and nurse coordinator will discuss treatment for your baby and answer any questions you may have when you come to the Janeway.

<table>
<thead>
<tr>
<th>Lip Repair Surgery</th>
<th>3 - 6 months (approximate)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palate Repair Surgery</td>
<td>12 months (approximate)</td>
</tr>
</tbody>
</table>
Before surgery - Bilateral Cleft  After surgery  At 6 years

Before surgery - Unilateral Cleft  After surgery
Procedures to help prepare for surgery

Some babies require special taping and/or nasal alveolar molding appliances (NAM) before surgery.

**Taping**

Surgical tape is sometimes used to hold the sides of the lip together so they are in better position for the plastic surgeon when the lip surgery is done. The team nurse coordinator will show you how to place the tape if it is needed for your baby.
Obturator / Nasal Alveolar Molding appliance (NAM)

Your baby may need a special plate called an obturator to temporarily close off the cleft in the palate. An obturator is made by the pediatric dentist from a mold of your baby’s mouth and helps prevent milk from escaping through the nose while feeding. An obturator can also serve as a NAM or nasal alveolar molding appliance. A NAM appliance is an obturator with a tiny plastic bulb attached. The plastic bulb helps shape or mold the baby’s nose and palate prior to surgery. An obturator/NAM is comfortable for your baby to wear and most babies get used to them very quickly. If an obturator/NAM is needed, it is most often used from birth up to the operation to close the lip. If the obturator is still needed after lip surgery, a new appliance is made.
AFTER SURGERY

Restraints
After surgery, restraints are used on the baby’s arms to keep the child from rubbing the lip or putting hands in mouth. The nurse will show you how to place them properly.

Baby wearing arm restraints after surgery
Pre and Post Surgery
Pre and post surgery of different babies
Pre and post surgery
Julia’s Story

The Team was inspired to include this story told by the mom of one baby girl.

Julia Young, 1 year old - and her mother
One day, a few years ago, a baby girl was born in a small community in Newfoundland. She was the third child and the third daughter for the family.

They decided to call her "Julia"

Julia’s arrival was uneventful except she had a cleft lip and palate. Her parents did not know about it before she was born. There was no family history and neither Mom nor Dad had ever seen anyone with a cleft lip or palate.
We were so shocked when we saw Julia’s face, it took away some of the joy we felt when our other daughters were born. The doctor’s and nurses told us she was a healthy baby and that surgery would correct the problem. We just couldn’t see how that would happen.
One of the nurses in the delivery room told us that her brother was born with a cleft lip and palate. This wonderful caring person wanted to reassure us so much that she actually left the hospital and went home to bring us back a picture of her brother.

He was an adult in the photo so it was difficult to imagine what his face looked like when he was born but we knew there was hope.

Once Julia’s surgery was complete, we were very happy with the results.
I would like to help reassure other families, so ever since Julia’s birth I have given photos of her to members of the cleft lip and palate team at the Janeway. They say they have more pictures of Julia than any other child.
Team Comment: Julia was born more than seven years ago. Each year more babies with cleft lip and palate are born to parents without prior knowledge of the condition. It would be wonderful to have pictures such as those Julia’s mother has lovingly provided for all parents who find themselves in this difficult situation.

We would like to see copies of this binder in each hospital in Newfoundland and Labrador that provides labour and delivery services.
Types of Cleft Lip and Palate

Clefts of the lip and palate (roof of the mouth) vary in severity from one baby to the next. While most babies have both cleft lip and palate, some have only one. Clefts may occur on one or both sides. The basic types of clefts are described below.

Cleft lip

The lip may be cleft on one side (unilateral) or both sides (bilateral). When a one-sided cleft goes all the way through the lip, the baby’s nose tends to look spread out. Plastic surgery on the lip helps make the nose look more normal.

When the lip is cleft on both sides, the cleft may go through the gums, making the center part of the lip and gums swing upward and look pushed out. Sometimes treatment is started simply by using tape to bring the tissue into a more normal position. Children with bilateral clefts may need more than one operation to make the lip as normal as possible. The first operation is usually done in the early months of life.

A two-sided cleft is harder to treat because less tissue is available for the plastic surgeon to work with when closing the cleft. Also, when the baby’s teeth come in, some may be missing or poorly formed in the area of the cleft.

**Cleft Palate**

A mild case of cleft palate may consist of little more than a notch in the soft palate at the back of the mouth. In moderate cases, the clefts are somewhat longer, extending from the back of the mouth to the place where the soft and hard palates join. In severe cases, the cleft may run the entire length of the root of the mouth. Clefts of the lip often occur along with cleft palate.

More Photographs
Stories of Newborns with Cleft Lip and Palate through images

Unilateral complete Cleft Lip and Palate, pre and post surgery

Unilateral incomplete Cleft Lip and Palate, pre and post surgery
Bilateral complete cleft of lip and palate, pre and post surgery
Incomplete bilateral cleft lip, pre and post surgery
“I think this binder is a really good idea. When Julia was born the staff did not know how to feed the baby and there was talk of airlifting her to the Janeway. That really frightened my husband and I.”

— Brenda Young, mother of Julia Young

“My daughter Mackenna was born with the condition Pierre Robin Sequence. It involves having a cleft palate and a recessed chin. Not knowing anyone who suffered from this, we turned to the Internet for information about PRS which helped and also frightened us. Though Mackenna spent over two months in the NICU and PICU with feeding and breathing issues, I am ecstatic to say that she is now a happy and very healthy four month old. There really is a light at the end of the tunnel!”

— Sharlene Johnson, mother of Mackenna Johnson
Resource & Contact Information

Janeway Children’s Health & Rehabilitation Centre
Janeway Cleft Lip, Palate and Craniofacial Team
  Nurse Coordinator: (709) 777-4661 or (709) 777-4005
  Parent Support Representative: (709) 777-4661
  Pediatric Telephone Advice Line: (709) 722-1126 or 1-866-722-1126
  General Inquiries and Patient Information: (709) 777-6300
  Emergency: (709) 777-4575
  Website: www.easternhealth.ca
  Address: 300 Prince Philip Drive, St. John’s, NL A1B 3V6

AboutFace
A Canadian and International Organization for people with facial differences and their families.
  Website: www.aboutface.ca
  Toll Free: 1-800-665-3223

Cleft Palate Foundation
Information for parents and caregivers
  Website: www.cleftline.org
  Toll Free: 1-800-242-5338
Bibliography


An early intervention guide to infants born with clefts. (includes abstract); Savage HE; Infant-Toddler Intervention, 1997 Dec; 7 (4): 271-84 (journal article - pictorial, tables/charts) ISSN: 1053-5586 CINAHL AN: 1998047302
Cleft lip and palate: what nurses can do to educate and reassure parents. Uhrich KS; Mackin AL; American Journal of Nursing, 2001 Mar; 101 (3): Critical Care Extra: 24AA-BB, 24EE, 24GG passim (journal article - case study, pictorial) ISSN: 0002-936X CINAHL AN: 2001034876

Management of infants born with a cleft lip and palate. Part 2; Bannister P; Infant, 2008 Mar; 4 (2): 57-60 (journal article - pictorial, tables/charts) ISSN: 1745-1205

Management of infants born with a cleft lip and palate: part 1; Bannister P; Infant, 2008 Jan; 4 (1): 5-8 (journal article - pictorial, standards, tables/charts) ISSN: 1745-1205

Prenatal cleft lip and palate parent programme -- phase 2.(includes abstract); Martin V; British Journal of Midwifery, 2005 Feb; 13 (2): 96-100 (journal article - pictorial, research, tables/charts) ISSN: 0969-4900

Prenatal cleft lip and palate parent programme -- phase I.(includes abstract); Martin V; British Journal of Midwifery, 2005 Feb; 13 (2): 90-5 (journal article - pictorial, research, tables/charts) ISSN: 0969-4900

Right from the start... cleft palates.(includes abstract); Alderman C; Nursing Standard, 2000 Dec 6-12; 15 (12): 16-8 (journal article) ISSN: 0029-6570 PMID: 11971581
Appendix

List of attached resource materials:

1. General Information

2. Feeding
   2.1 Pamphlet — Breastfeeding Your Baby, Newfoundland & Labrador, 2007
   2.2 Pamphlet — Infant Formula (Breastmilk Substitute) Feeding, Government of Newfoundland & Labrador, 2008
   2.5 Publication — Facing it Together, Book and CD, About Face International
Newborns with Cleft Lip and Palate
A Resource for Health Professionals and Families

1. Did you find the content relevant and evidence based? Rating 1 2 3 4 5
2. Was the information presented in clear and concise manner? Rating 1 2 3 4 5
3. Did you gain any new knowledge from this presentation? Rating 1 2 3 4 5
4. Did the session meet your needs/expectations? Rating 1 2 3 4 5
5. Do you think you will find the binder useful? Rating 1 2 3 4 5
6. Will you follow up on ideas presented today? Yes ______ No ________
7. Would you recommend this session to other groups? Yes ______ No ________

8. What suggestions do you have to improve these sessions?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Families Evaluation

Newborns with Cleft Lip and Palate
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Name of Hospital or Health Center: ____________________________________________
Date: _______________________________________________________________________

Please rate this binder:

1- Excellent 3- Good
2- Very Good 4- Fair
5- Poor

1. Did you find the content relevant and evidence based? Rating 1 2 3 4 5
2. Was the information clear and concise? Rating 1 2 3 4 5
3. Did you gain any new knowledge from this information? Rating 1 2 3 4 5
4. Did the binder meet your needs/expectations? Rating 1 2 3 4 5
5. Will you use information provided in this binder? Yes ______ No ______
6. Would you recommend this binder to other families? Yes ______ No ______

7. What suggestions do you have to improve this binder? ____________________________________________________________
___________________________________________________________________________
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