Ankyloglossia Is It Real?

Patient Case Study

Presented by

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An International Midwifery Service

RN/IBCLC

Redlands Community Hospital

Personal Disclosures

- I have an Independent Midwifery Practice where I also provide Lactation support to women.
- I offer a fee for service practice, for those seeking lactation services.
- I have provided many PRO-BONO services to women seeking breastfeeding or lactation support.
- I am a Board Member of the IEBFC but have no financial relationship between this or any organization that could be considered a conflict of interest.

Objectives

- What is Tongue-Tie - (Ankyloglossia)?
- Why early identification is important and how correct management can help decrease maternal anxiety and improve her coping abilities during what can be, a very stressful time
- Goal is to increase awareness regarding the common maternal signs and symptoms of Ankyloglossia and lactation challenges they present for mother and baby
- Where are the professionals who can help in the management of this condition?
- Case Study that identifies some of the consequences associated to mis-diagnosis and management

Patient Case Study Presentation Disclosure

- This case study is presented with the full support and complete co-operation of the person in question, whom has given me full permission to use her real first name.

- April 26th 2016

What Is Tongue-Tie (Ankyloglossia)?

- **Ankyloglossia**, is a congenital oral anomaly which may decrease the mobility and function of the tongue. It is considered congenital because the condition has its own coding gene(s)
- According to the International Affiliation of Tongue Tie (IATP), Ankyloglossia is in fact, an embryological remnant of tissue, in the midline, between the undersurface of the tongue (linguinal frenulum), and the floor of the mouth which restricts normal tongue function
- Normally, the tongue is loosely attached to the base of the mouth with a piece of skin called the lingual frenulum

(Dr James Wright, Retired Paediatric Surgeon, Australia)

- In babies with born with tongue-tie, the linguinal frenulum, is unusually short and tight, and its restrictive function can prevent the baby from feeding properly.
- Often early signs of concern are the mothers complaints of unsustainable latch and/or persistent pain

Tongue Tie Prevelance

- Tongue-tie is a birth defect that affects 4-11% of newborn babies and is more common in boys than girls, but it's incidence in recent years has increased by approximately 33%.
- The clinical significance of ankyloglossia today however, remains controversial amongst health clinicians, which causes confusion for the mother and mis-management of care

Tongue – Tie Definition

- Elizabeth Edmunds' definition of Tongue-Tie:

Tongue-Tie is a congenital condition that negatively affects breastfeeding. The thickened, tightened or shortened frenulum affects the infant's ability to suck and frequently results in sore and painful nipples.

Elizabeth Edmunds-Understanding The experiences of Mothers Who Are Breastfeeding An Infant With Tongue-Tie –Dec 5th 2013

- Alison Hazelbaker (2009), defines Tongue –Tie as:

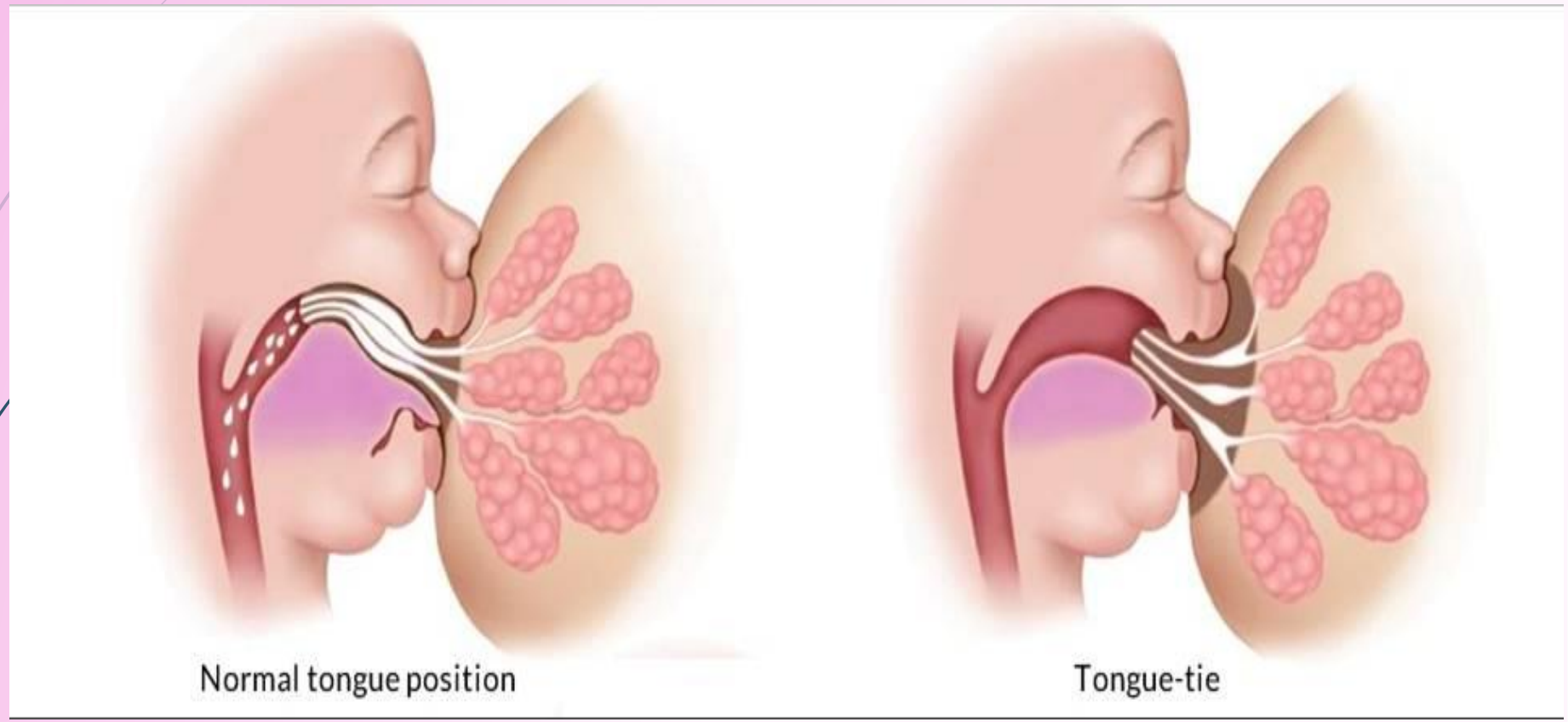
'a short and/or tight linguinal frenulum that, to one degree or another, adversely affects proper tongue motion'

The Tongue's Purpose

- Contrary, to common belief, the tongue's appearance is actually secondary to it's function
- However, to avoid functional deficits the tongue MUST be able to:
  - Move up and down
  - Move freely from side to side
  - Cup the breast to help sustain latch
  - Spread well without humping
  - Protect the airway through adequate function

- In the early moths of life, ankyloglossia can pose great challenges for both mom and baby, in terms of feeding
- However, because there are so many variants to this condition, it makes definition and diagnosis very difficult and challenging
- One of the main infant symptoms reported by moms is the inability to sustain latch

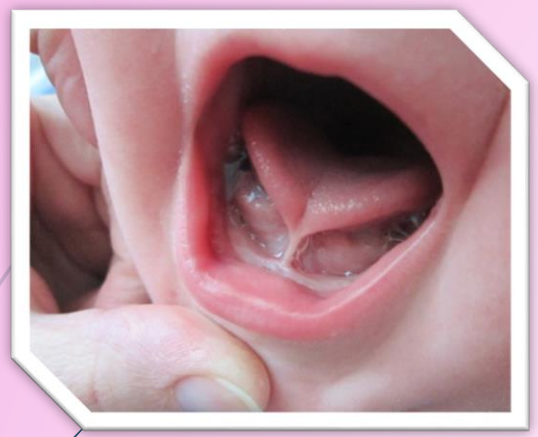
Why Is Sustainability Of Latch Difficult When Tongue-Tie Is Present?

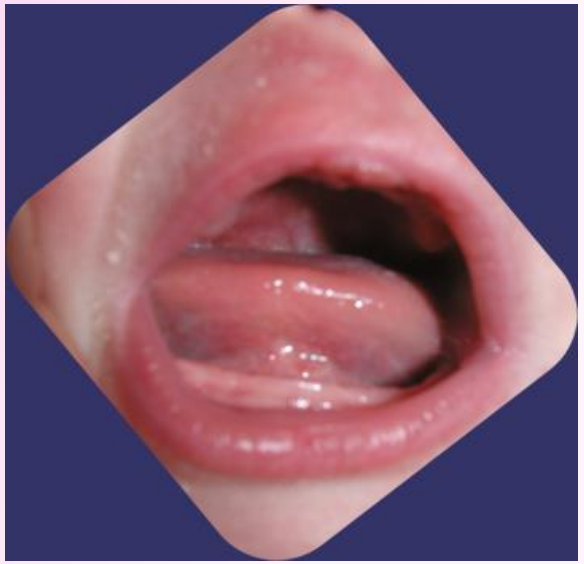


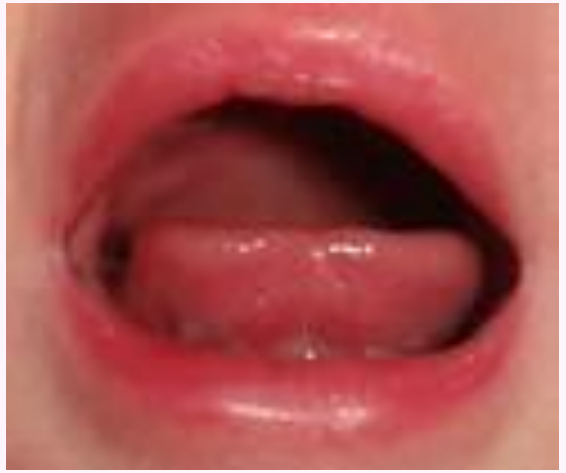
Picture Courtesy of Dr Neville Wilson: http://drnevillewilson.com/

- Poor seal with tongue causes ingestion of air
- This causes excess flatulence, GI disturbances, reflux is likely
- Contributes to infant's being unsettled

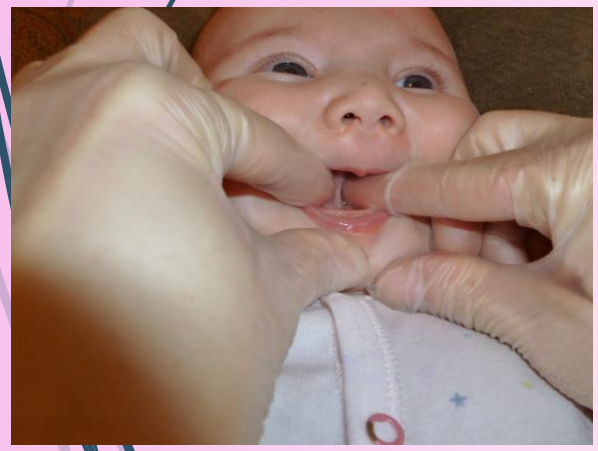
What Does Tongue – Tie Look Like?

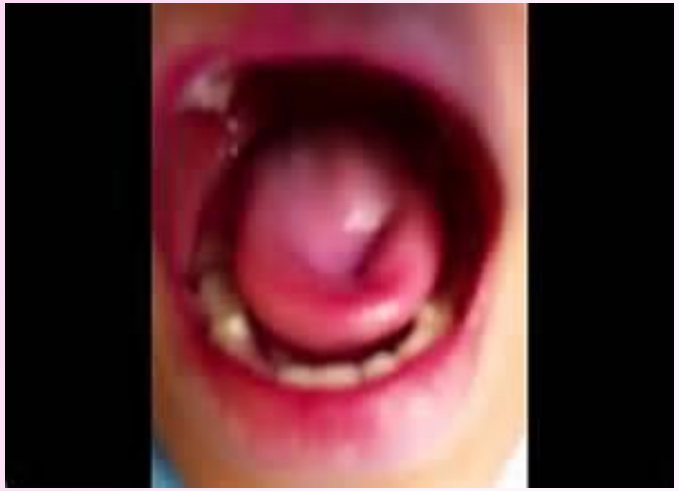




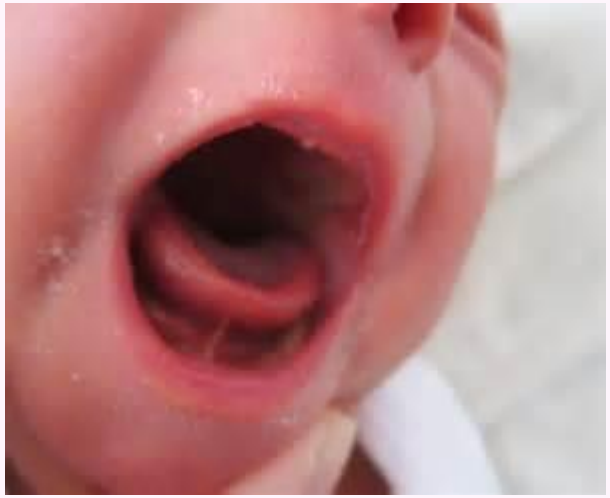


Many Variations of Tongue-Tie

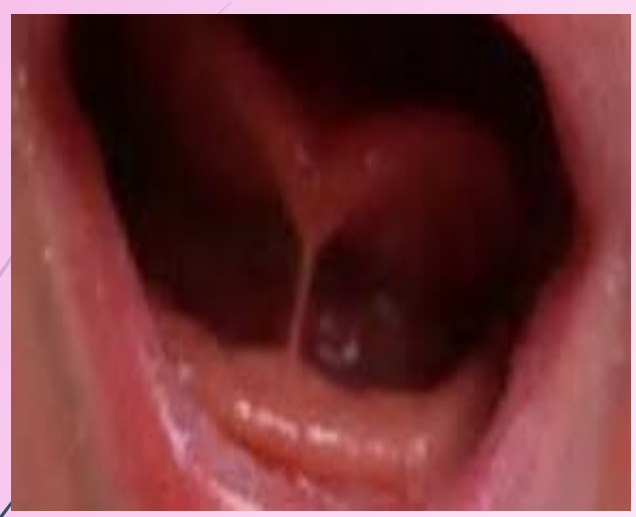




Tongue Humping

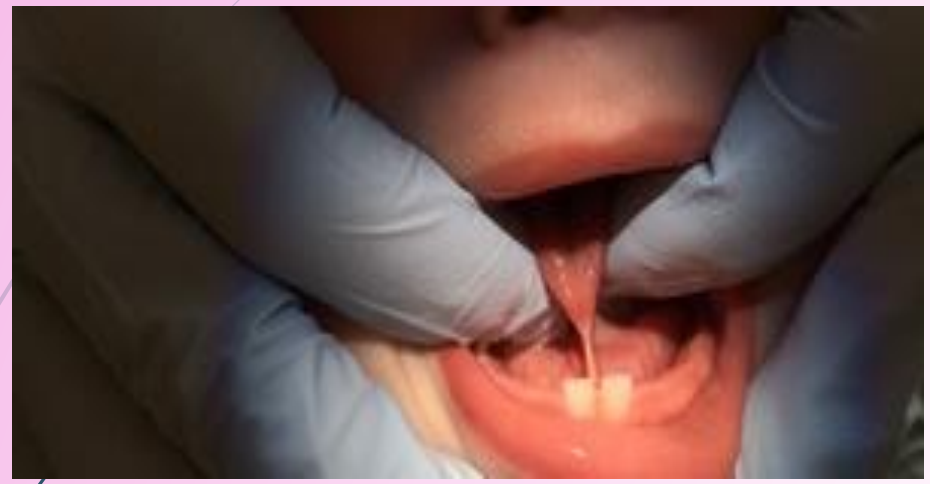


Unable To Lift The Center Of The Tongue

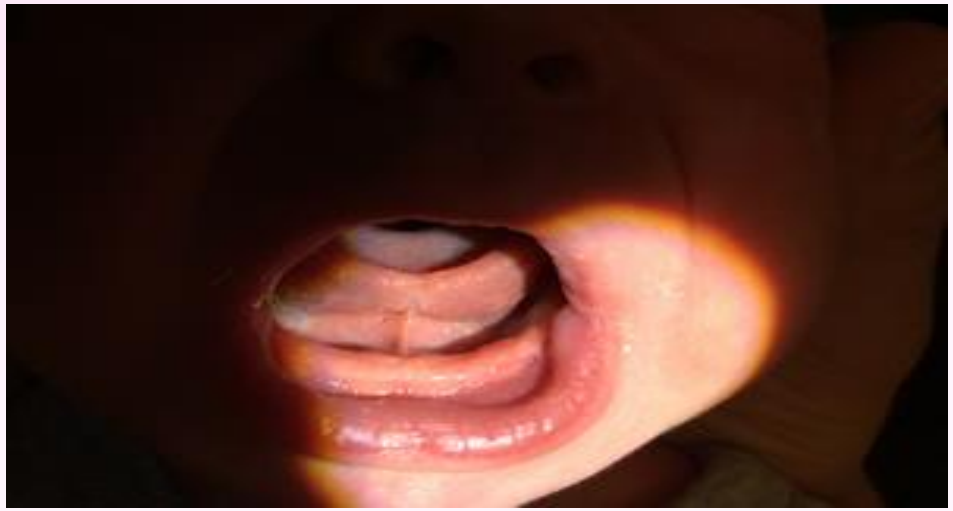


Pictures Courtesy Alison HazelBaker (2009)

Tongue Tie Categories



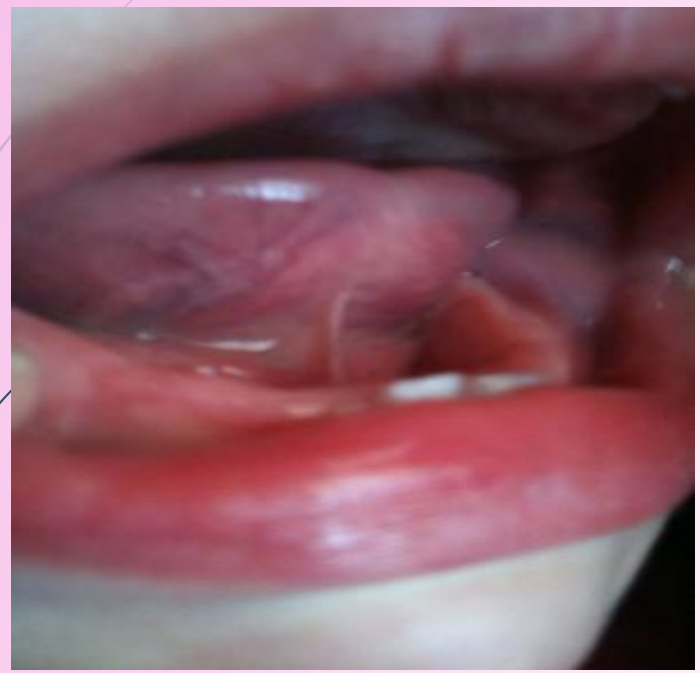
Class 1
Easiest to diagnose and perhaps the only one some clinicians consider worthy of treatment



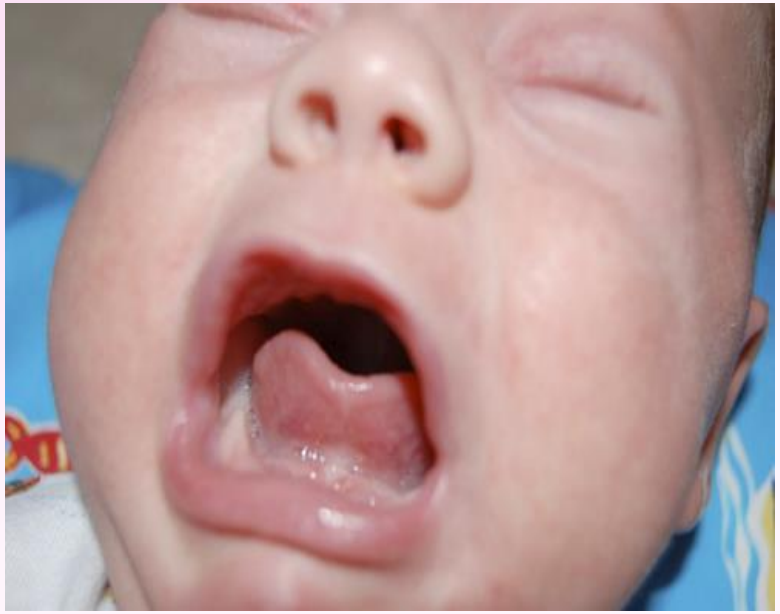
Class 2
Considered to be an anterior tie, as the tie inserts just behind the tip of the tongue. Note the slight cleft appearance of the tongue, centrally

Pictures courtesy of Dr Bobby Ghaheri (2014)

Tongue Tie Categories Contd…



Class 3
Classified as a posterior TT
Note the visible membrane



Class 4
Note the uneven tongue, poor central lift, thin membrane present. The most commonly missed and mis-diagnosed tie

Pictures courtesy of Dr Bobby Ghaheri (2014)

Why Is Tongue Function Important

- The tongue helps palatal development during embryogenesis and fetal life
- Intra-oral pressure is generated by tongue function which helps facilitate milk transfer
- The Tongue starts the digestive sequence
- The tongue directs food into the oral cavity and then into the throat
- The tongue protects the airway
- Eating should be effortless

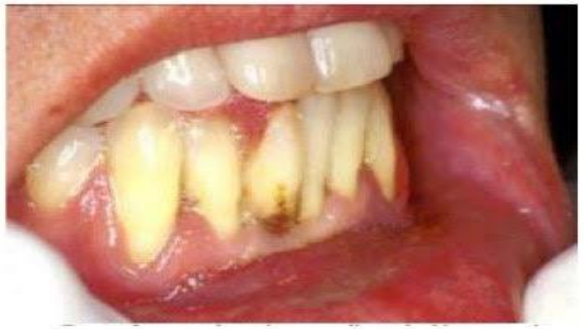
Impact on Breastfeeding

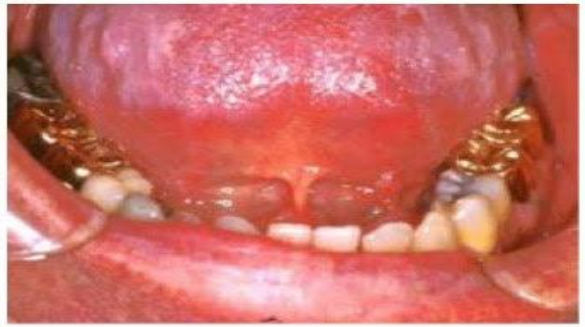
- Inability to sustain a latch
- Poor suck-swallow-breathe co-ordination
- Poor seal
- Lengthy but unsatisfied feeding
- Fatigue
- Excess drooling
- Probable damaged nipples reported in 50% of moms affected
- Poor milk supply
- Increased likelihood of neonatal jaundice requiring phototherapy
- Possible poor weight gain
- Premature weaning likely
- If tongue-tie is severe, feeding from any vessel can be challenging

Impact on General and Oral Health

- Poor jaw development
- Tongue thrust and functional imbalances
- Floppy airway/risk of airway obstruction
- Drooling/excessive salivation
- Dysphagia
- Delayed Speech
- Muffled speech
- Jaw clench
- Neck tension
- Headaches
- Embarrassment to speak as one gets older
- Depending of type of tongue-tie, difficulty licking an ice cream may be hard (Category 1)

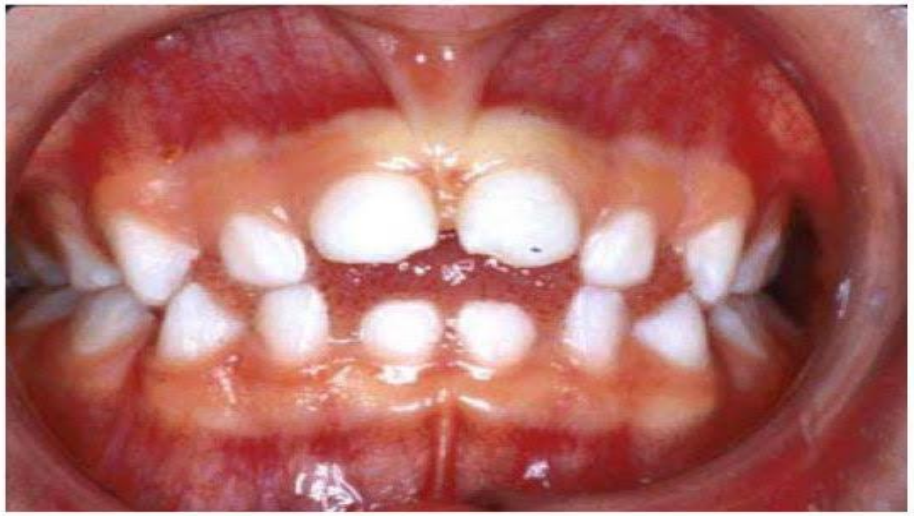
The Long Term Effects of Untreated Restrictive Linguinal Frenulum In An Adult





Obstructive Sleep Apnea

Decay and loosening due to tongue thrust



Tongue thrust malocclusion

Dental Decay And Periodontal Disease

Pictures Courtesy Alison HazelBaker (2009)

Case Study

History

- Kristin was a 29 year old, white, Native American woman
- Gravida 1, Para 1 - Unremarkable Medical History
- No known allergies
- Uncomplicated Pregnancy
- She prepared for her birth and new role as a mother by reading, watching multiple videos, and planned her birth with great resource and excitement
- Her baby was born at a local hospital

- Kristin's labor was electively induced at 40 weeks +5 days per MD request
- She was in labor for 19 hours and she pushed for 3 hours
- The birth was complicated by a shoulder dystocia
- A live male Infant was delivered in good health with Apgar scores of 9/1 min and 9/5 mins, weighing in at a healthy 8lbs 8oz
- Baby was assessed and placed on mothers chest to initiate skin to skin contact.
- Kristin recovered well with no postpartum complications.

Hospital Breastfeeding Experience (Day 1)

- Kristin had chosen to breastfeed her baby. The labor ward RN, assisted with first latch
- This experience seemed to be positive.
- When in the postnatal ward, the RN's whom would 'glance' over her, while baby was breastfeeding, provided Kristin with positive feedback
- As time passed, Kristin began to experience pain when infant would latch to breast
- Kristin noticed a persistent "clicking" sound while baby breastfed
- The baby would feed for long periods but always appeared unsettled and hungry

- During baby's 24 hour screening assessment, the RN placed a gloved finger in the baby's mouth, to help soothe him during his exam, and noticed that the baby was biting her finger instead of sucking it.
- The RN asked Kristin if she felt the baby was biting her while breastfeeding.
- Despite the RN's identification of the baby biting, no further communication, education or interventions were offered during the remainder of their hospitalization
- As nursing staff did not seem to be concerned regarding this experience, Kristin did not seek additional support from a lactation consultant while in the hospital. She put this down to being a normal adjustment to breastfeeding and something that would soon pass.

Breastfeeding When Home (Day 2)

- The "clicking" sound persisted, the pain while breastfeeding was 10/10, and Kristin noticed that at the end of each breastfeed, she would have misshapen nipples, that were now red, cracked and swollen.
- Milk production was actually good. Kristin was pumping so she could build up a milk supply, and was already able to store colostrum.
- Baby cried a lot, always appeared hungry, parents were unable to soothe him and he did not sleep more than a few minutes at a time around the clock.
- Both Kristin and her husband were exhausted

Well Baby Visit With Pediatrician (Day 3)

- Kristin, accompanied by her husband, informed their pediatrician of her worsening nipple pain, difficulty sustaining a latch, and expressed concerns over this 'clicking' noise while breastfeeding, and how baby seemed to be "colicky"
- Kristin was encouraged to breastfeed baby while at the appointment, so her Pediatrician could observe the feed
- The Doctor, "hovered" over her, and stated that the baby was just fine because he was not loosing weight. He just needed to flange his lips more, and Kristin could always supplement with bottles
- All this information was being given, but no one had actually examined the baby's mouth to check everything was alright with him

Milk Supply

- When Kristin's milk came in, the let down was fast. The baby sounded as though he was choking on the milk, while he was feeding.
- Over the next few days, Kristin noticed that the baby had started to develop 'colic' like symptoms which caused him to be more unsettled than before
- He would drool constantly, was very gassy and fussy, never satisfied and had difficulty burping.

Weeks 1 and 2

- Engorgement occurred
- Latch continued to be painful
- Nipples were damaged and painful
- Baby's symptoms persisted and his ability to breastfeed became more and more challenging
- Pumping continued and supplementation of breast milk via bottle began, but the drooling continued along with his inability to be soothed

Weeks 2-3 of Life

- Exhausted
- Sleep deprived
- Unable to breastfeed
- Already treated for mastitis
- Kristin started to become depressed
- They returned to the Pediatrician where again she was advised to 'Give the baby a bottle' and to go to the hospitals outreach clinic to see a lactation consultant
- However, in contacting the clinic, Kristin was told she had to wait 2.5 weeks for and appointment

Week 2-3 of Life Contd…

- Kristin's husband, who was a huge part of her breastfeeding support and encouragement, would not be able to accompany Kristin to this appointment
- So she declined to attend…
- Together Kristin and her husband continued reading and watching YouTube videos about breastfeeding
- She followed the instructions perfectly, yet her baby still, could not breastfeed

Postpartum Check Up

- Parenting was not at all what Kristin and her husband had envisioned
- Now almost 4 weeks postnatal, Kristin awoke and was experiencing depressive thoughts. Luckily she shared this with her mom, who immediately called her OB, and was seen that same day
- Kristin discussed her breastfeeding difficulties and how this was causing her to wish her baby boy had never been born, and of how she felt he had 'robbed' her of her body/marriage/life.
- The OB, examined Kristin, and felt Kristin just needed more rest, along with the support of a lactation consultant.
- Kristin googled local lactation consultant's and was able to schedule a private consultation for the next day.

Feelings Of Inadequacy Setting In

- Parental vision shattered
- Comments made by 'professionals' did not add up
- Baby is ok. Mom is ok. So why could she not feed her baby?
- Everything appeared to be sugar coated with:

'*Just give him a bottle*' – Yet he couldn't really feed properly from the bottle either!

(Per Kristin - "These words "**Just Give Him A Bottle**" became the most offensive thing that anyone could have told me")

- As a new mother, non medical clinician, I knew something was wrong, so why didn't the experts know this too?
- Yet because she's not an expert in the field, and a first time mom, she felt obligated to believe the professionals. Unfortunately, this became one of the main contributing factors as to why Kristin started to feel inadequate.

In Search Of An Answer

- Kristin needed to understand why her baby could not breastfeed or even take breast milk from a bottle without drooling
- Things just did not add up:
  - If she had 'perfect' breast anatomy, and
  - there was nothing wrong with the baby, then
  - why could the two of them not connect?

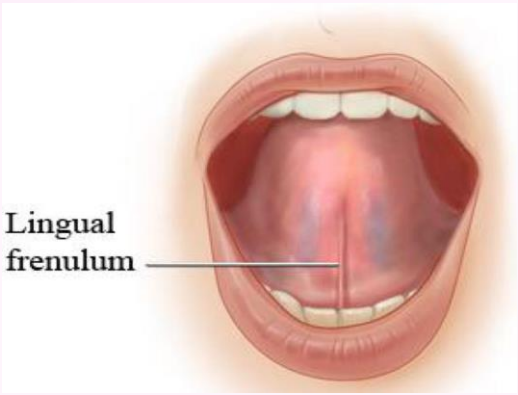
First Meeting With Nurse Midwife Lactation Consultant

- Kristin now almost 4 weeks postpartum
- Physical Appearance (Parents) – Exhausted, fatigued
- Psychological – Both parents looked sad and unhappy
- Baby in car seat, covered over with blanket, crying, but had a very distinct noisy sound
- The noises baby made, were so loud, he sounded like a train

Consultation of Mother Baby Dyad

- Clinical assessment of breasts – Findings:
  - Engorgement
  - Compression lines
  - Scabs
- Psychological Evaluation – Findings:
  - Kristin stated she "hated" breastfeeding. She hated the fact that she hated it, and hated herself for not being able to adequately provide nourishment for her baby, by breastfeeding
  - ***Kristin also confirmed that her depression was becoming more intense and had started to have suicidal thoughts***

Lactation/ Infant Feeding Consultation (cont…)



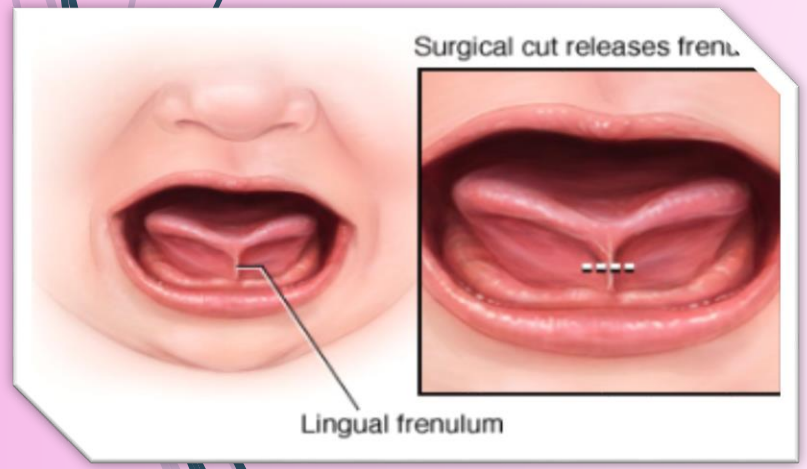
- Infant oral assessment and breastfeeding observation:
  - Palate, unremarkable
  - Labial frenulum elastic, and functional
  - Upper lip flanged well
  - Hyper-salivation and constant drooling noted
  - Tongue thrusting
  - Upon more detailed examination of infant's mouth, an inco-ordinated and disorganized suck was present with poor cupping ability
  - Unable to lift tongue
  - Very unsettled infant, fussy at breast, unable to attain/sustain latch
  - Initial assessment and observation suggested that the infant was tongue tied
  - **Patient stated** "that is the first time anyone has put their finger in his mouth"

Options

- Upon determination that the infant was in fact tongue tied, Kristin and her husband were provided with the following 4 options:
  1. Do Nothing
  2. See another Pediatrician
  3. Consult with a Pediactric dentist for further evaluation
  4. Consult with an ENT specialist for evaluation
  5. Proceed with Frenotomy procedure

Frenotomy

- The linguinal frenotomy was carried out in the office with the aide of sweet-ease (glucose water) for comfort
- The procedure was uncomplicated and completed within a matter of minutes
- Kristin was asked to breastfeed immediately post procedure for infant comfort and re-assessment. The suck was more organized, stronger, managed to sustain latch, no snapback or gasping present
- Kristin still experienced some pain during this breastfeed; however, she stated it was more tolerable and felt that this was due to the existing trauma on her nipples



Follow up

- Daily follow-up by phone as needed for continued support
- Kristin reported that her feedings became shorter in duration and that her baby was much more satisfied and needed to be fed less often per day, than before. Now having multiple wet and soiled diapers
- Kristin stated that there was less milk when pumping because her baby was now emptying her breasts during the feeds.
- Infant was soothing easier, even though he was still a little gassy. He was now sleeping 2-3 hours at a time, for the first time since birth.

Follow Up Continued…

- At 1 week post frenotomy, Kristin was experiencing a burning like pain and pins and needle in breasts and nipples.
- She was diagnosed with candida (yeast) infection of the nipples which was promptly treated with antifungal medication and the symptoms soon decreased.
- Kristin shared that her suicidal thoughts had diminished along with her exhaustion.
- Both she and her husband now felt as though they could now enjoy their infant, and their new family life, for the first time since his birth.

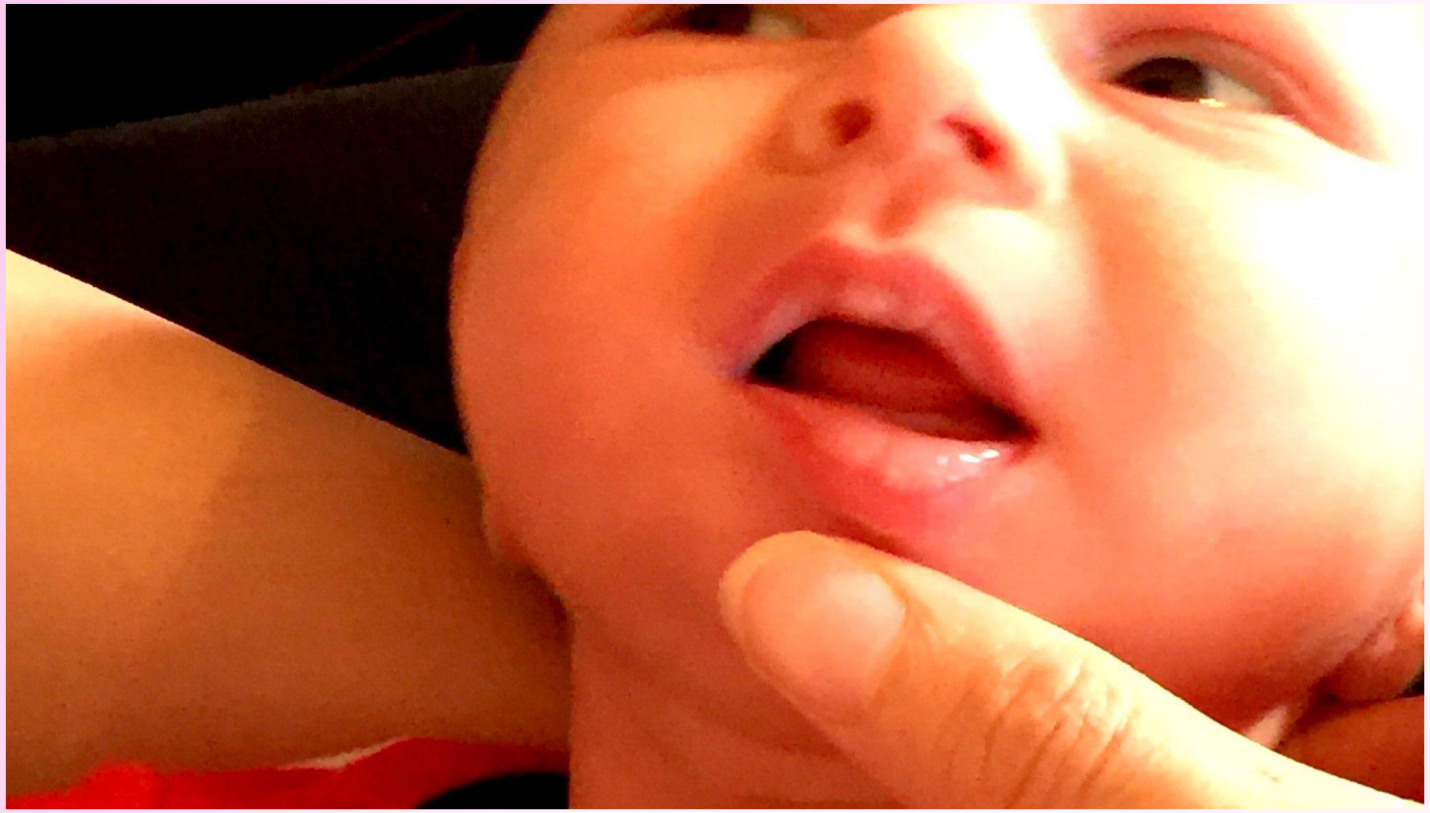
- I am happy to be able to share with you, that at 14 months after birth, Kristin is still breastfeeding and enjoying the bonding relationship she has developed with her baby
- Had the frenotomy not have been performed, it is highly unlikely that this would be the circumstance today
- The initial impact of Kristin's inability to breastfeed her baby, could have had a very different outcome on her mental health, had she not have found a provider whom was able to help

The next set of photographs are posted with permission from one of my own clients to whom I am very grateful for permitting me to share these images with you.

Her written Consent Was Obtained

Thank You

Sucking Blisters

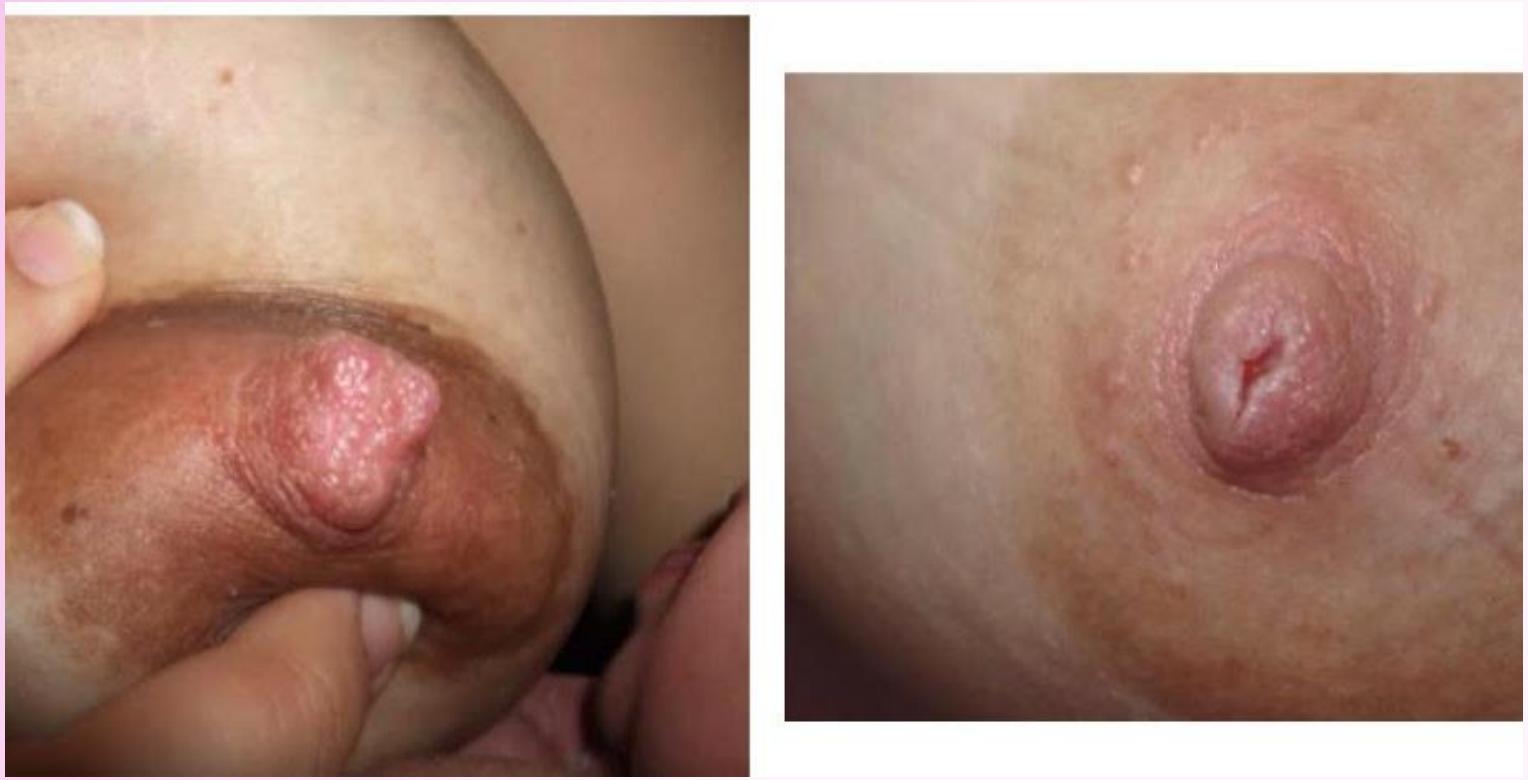


Photograph Courtesy Of Natalie Ann King, BA (Hons)
Documentary Photographer and Photojournalist

Poor Lateralization

Photograph Courtesy Of Natalie Ann King, BA (Hons)
Documentary Photographer and Photojournalist

Recognize The Signs



Photograph Courtesy Of Natalie Ann King, BA (Hons)
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Analgesics

Photograph Courtesy Of Natalie Ann King, BA (Hons)
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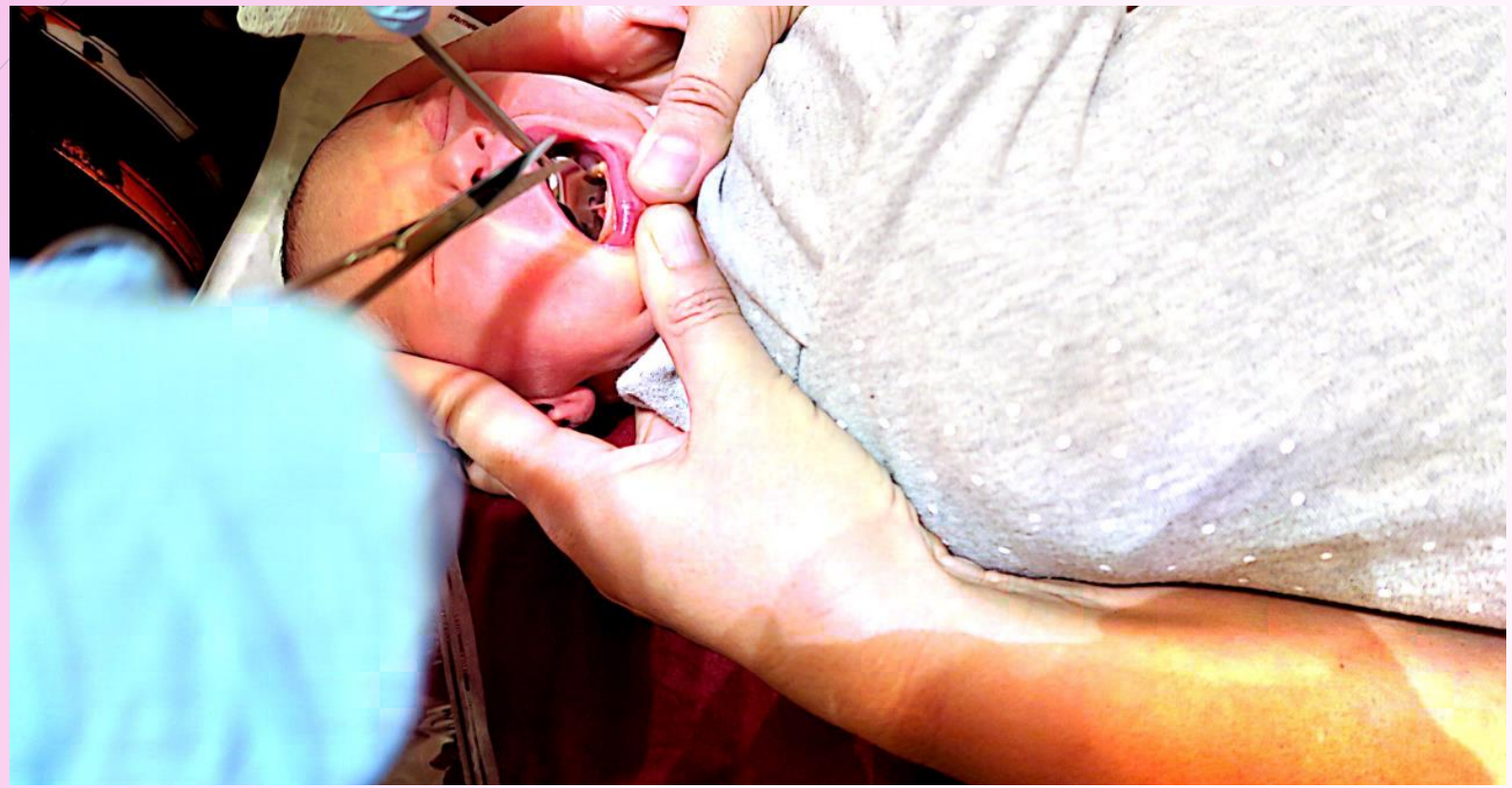
Frenotomy Clipping



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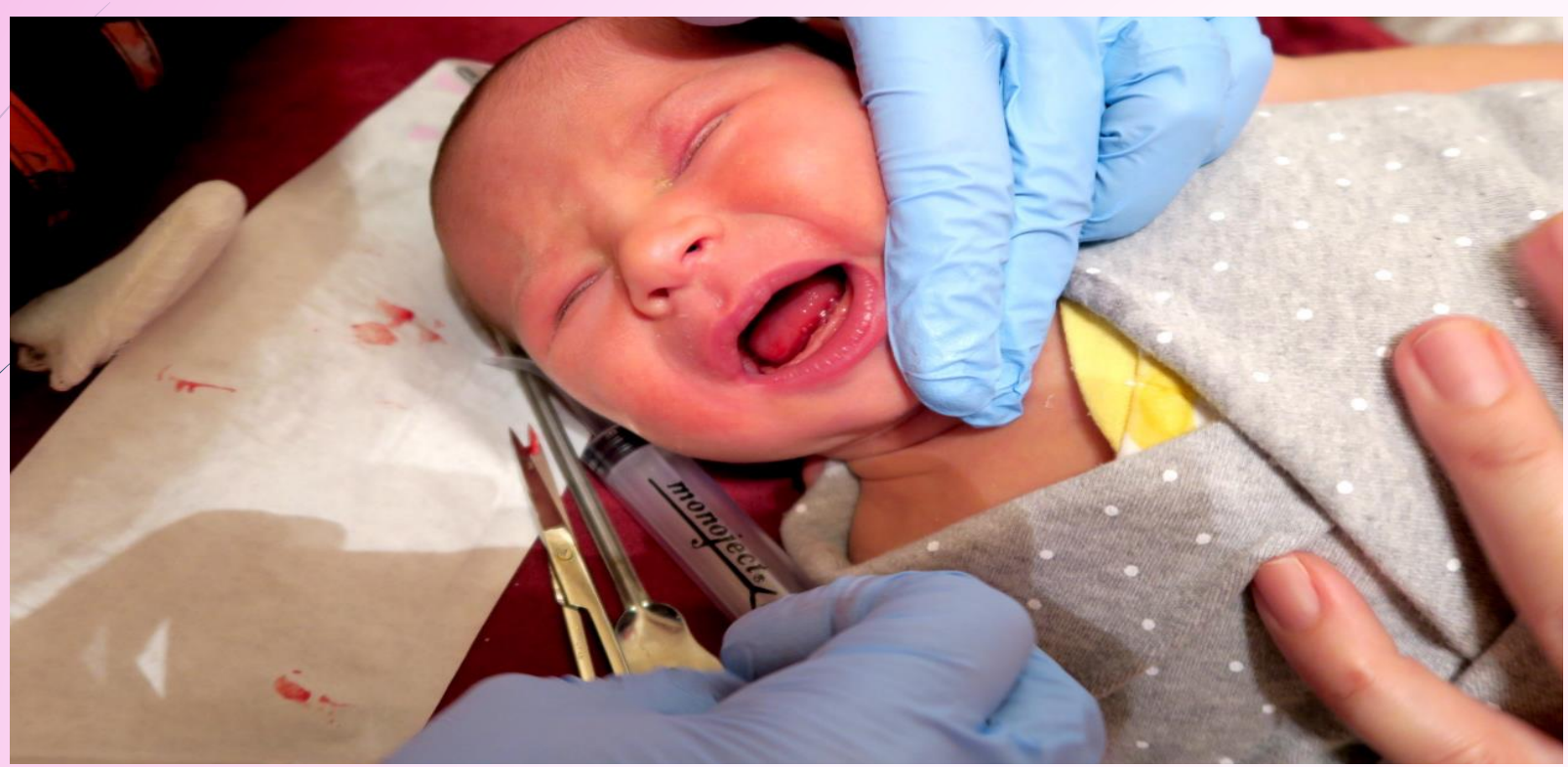
Spread of Tongue Improved



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Visible Tongue Lift Immediately Post Frenotomy

Photograph Courtesy Of Natalie Ann King, BA (Hons)
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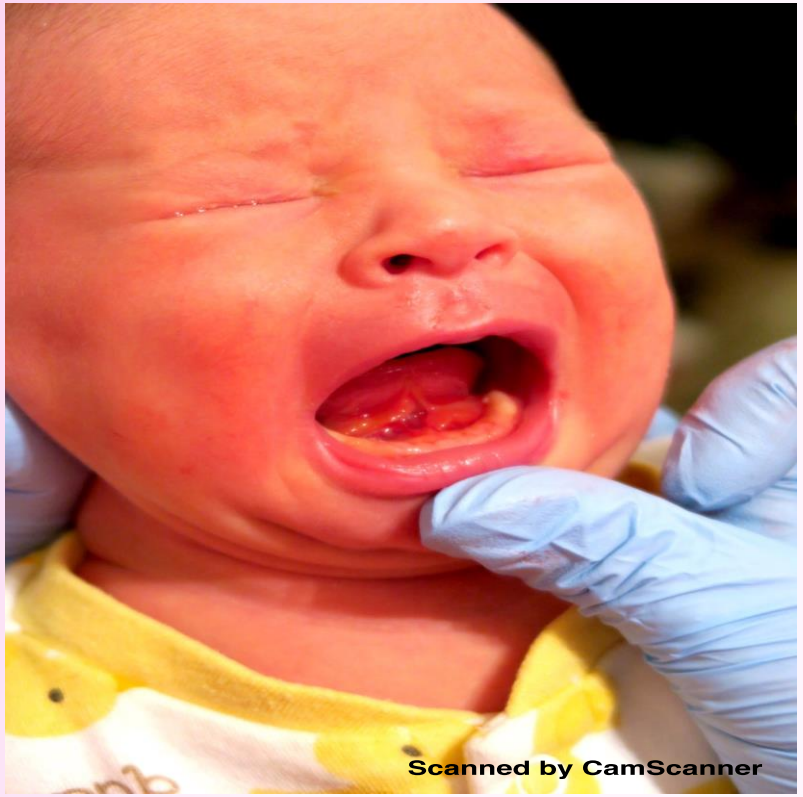
A Diamond-shaped Wound – Represents An Appropriate Release



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Documentary Photographer and Photojournalist

- As clinician's caring for this client group, we play a pivotal role, not only in the mothers ability to breastfeed her infant, but in her mental and physical health
- It is, I believe, our professional responsibility and duty to ensure we hear our moms, we listen to what they are telling us, and we take prompt and immediate action, to ensure they get the help and support they need
- We owe it to these ladies, to provide them with community support groups, where they can share their experience, learn from each other and know that they are not alone

Local Network

- Dr James Jesse
- Dr Judith Strutz (Cash only)
- Dr Taber
- Dr Fuller

(The above group of dentists perform Frenotomies on all categories of Ankyloglossia including Labial Frenulectomy via Laser)

- Dr Cohen and Dr Cuni (Beaver Medical Group)
- Dt Carter (Garden Pediatrics)

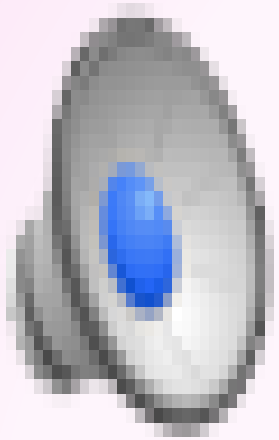
(The above group of Pediatricians only perform simple Frenotomies as in the category class 1, via clipping method-No labial frenulectomies performed)

- Maria A King – (Private Practice)

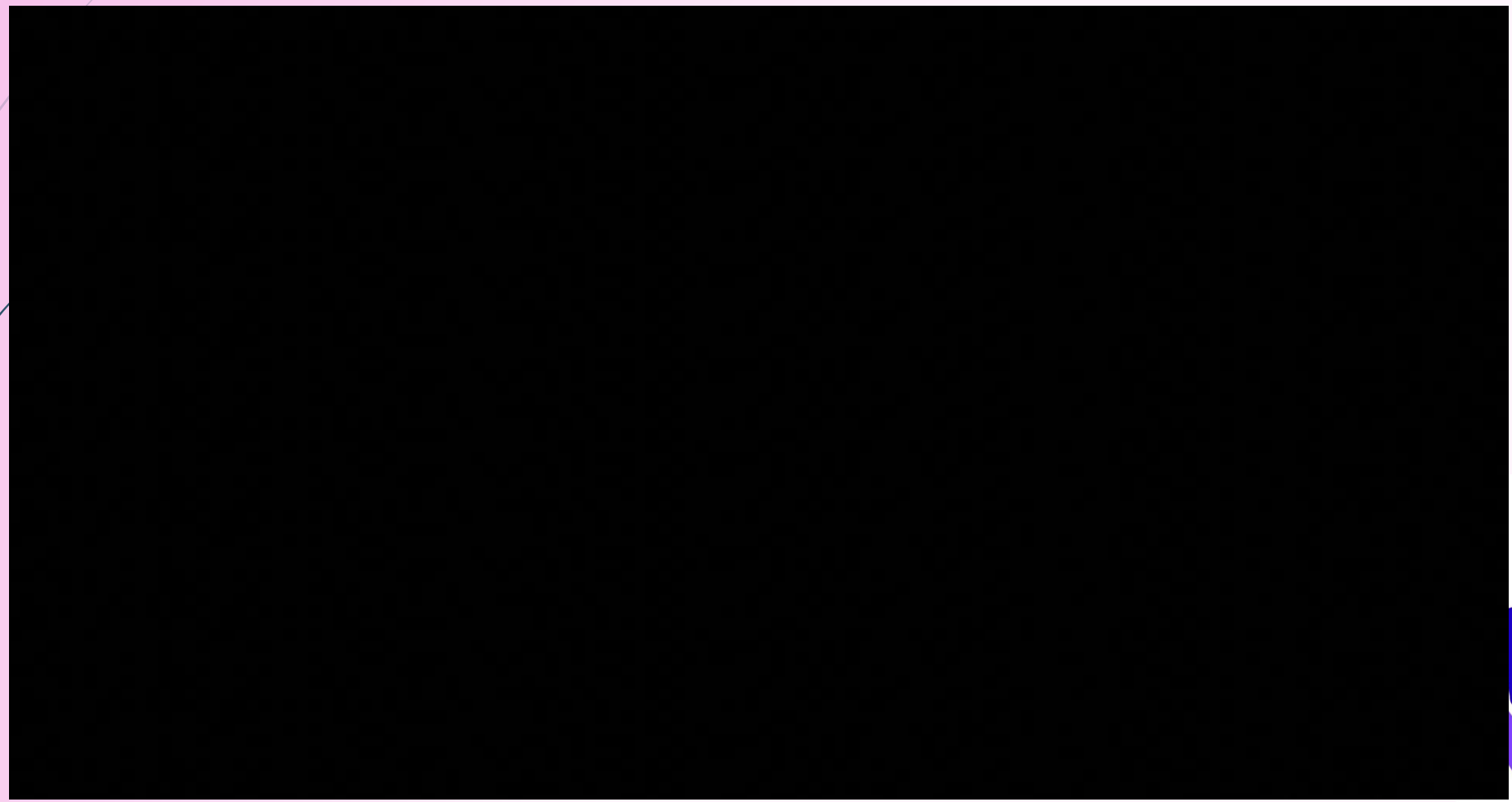
(Class 1-class 4 Linguinal Frenotomies only via clipping)

Videos From A Mom Of An Infant Born With Tongue-Tie And A Clinician Who Help Them

Apologies For The Amateur Footage



Videos From A Mom Of An Infant Born With Tongue-Tie And A clinician Who Help Them

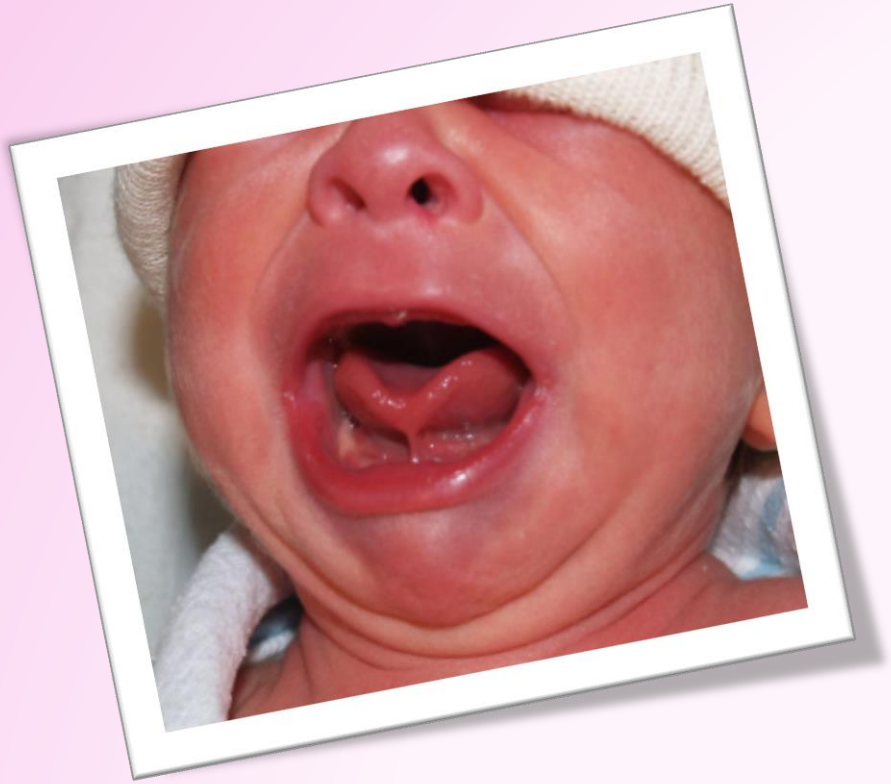


Summary

- Although ankyloglossia can be significant at birth, the severity and functional effects for those with less restrictive tongue function at birth, may actually decrease with time and oral growth.
- During the first 4 to 5 years of life, the oral cavity changes significantly in shape and size. The alveolar ridge grows in height, the teeth begin to erupt, and the tongue grows and narrows at the tip.
- Simultaneously, the lingual frenulum recedes, stretches, and may even rupture. Therefore, as a child grows, the severity of the tongue-tie lessens and the initial restrictions of lingual movement may diminish.
- While this is a reality, infants still need to be able to feed in order to sustain life, so the worst the tongue function is at birth, the greater the issue, and one that absolutely can not be ignored and/or brushed aside as insignificant because the tongue 'looks ok' visually.

- Clinicians must listen to the experts, the mothers. They are the ones whom can truly define the challenges they are faced with.
- National and International standardization and management of this condition is required in order for clinicians to provide offer **consistent** information regarding best practice recommendations/options available locally, to the women and babies whom entrust us with their health care needs.
- **As clinicians working within the maternal child health discipline, I believe, it is our responsibility and duty, to keep abreast of change and thereby drive the practice of change forward**

DON'T JUST LOOK…



Do something!

Speak Up

Question Concerns - Think Outside Of The Box
And
Improve Lives!

References

Actual patient case study (name not disclosed)

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Questions Welcome

Thank Your For Listening

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