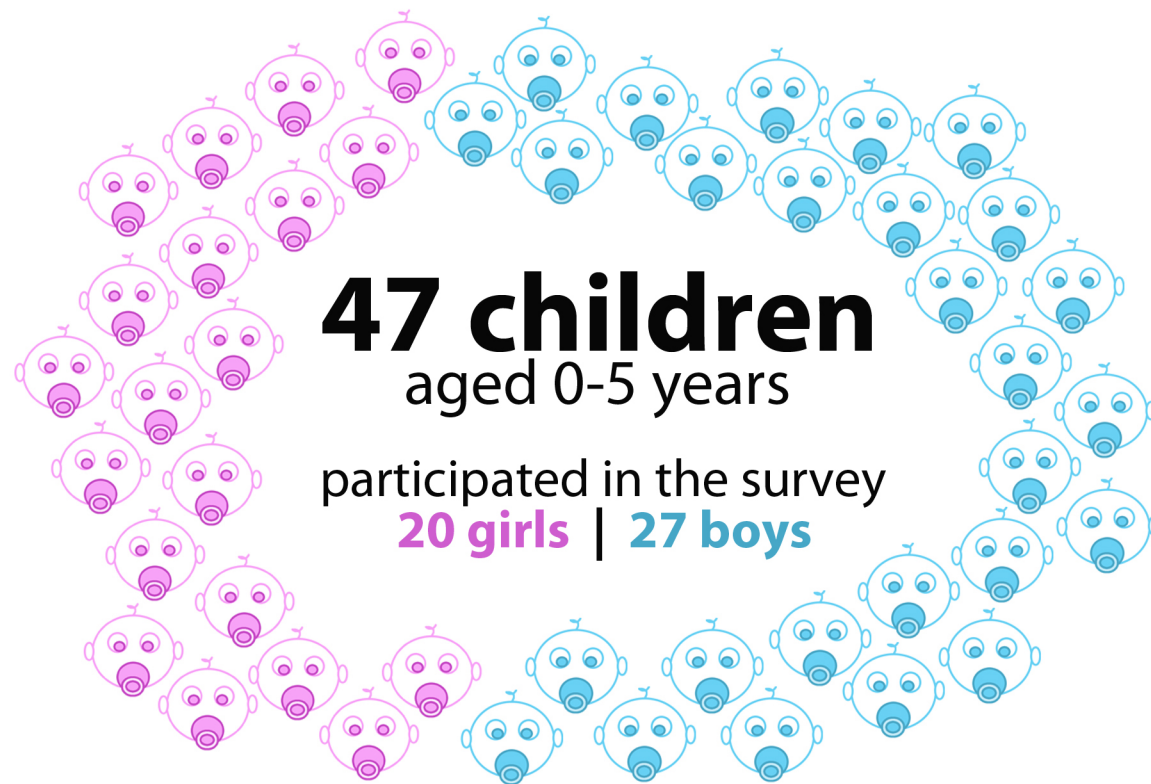


## SURVEY

# What effect does a PTT release have?

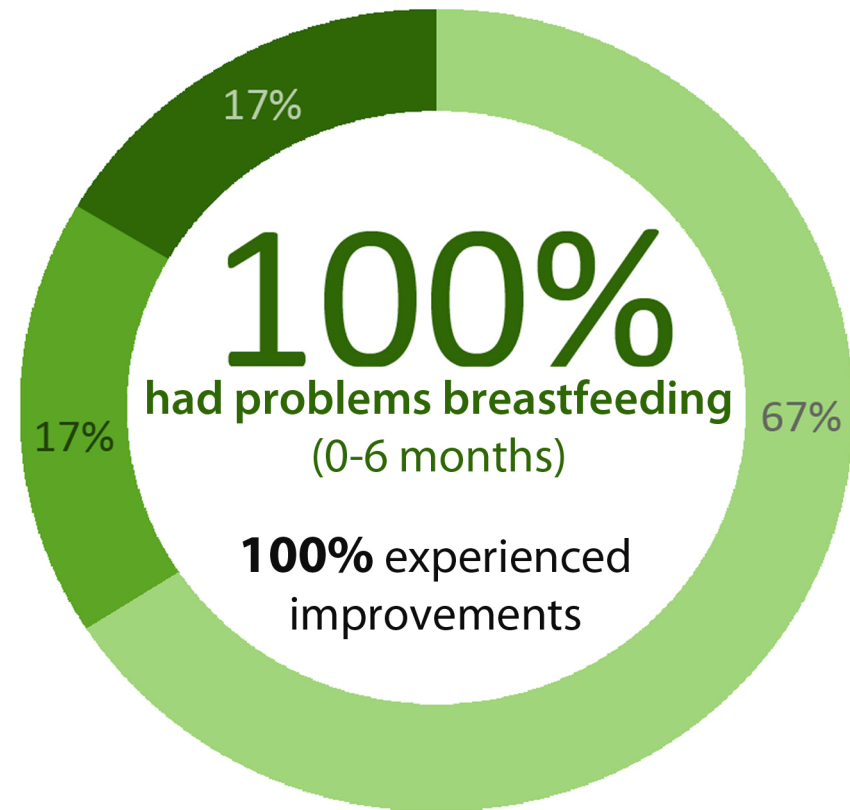
The results of this survey show that a release of a posterior tongue tie (PTT) can effect or solve various problems, like breastfeeding, digestion and bodily turmoil.



## QUESTION: Have the problems improved upon the release of PTT?

- Immediat improvement
- Improvement within a month
- Improvement after one month
- No change of symptoms
- Unsure
- Worsening of symptoms

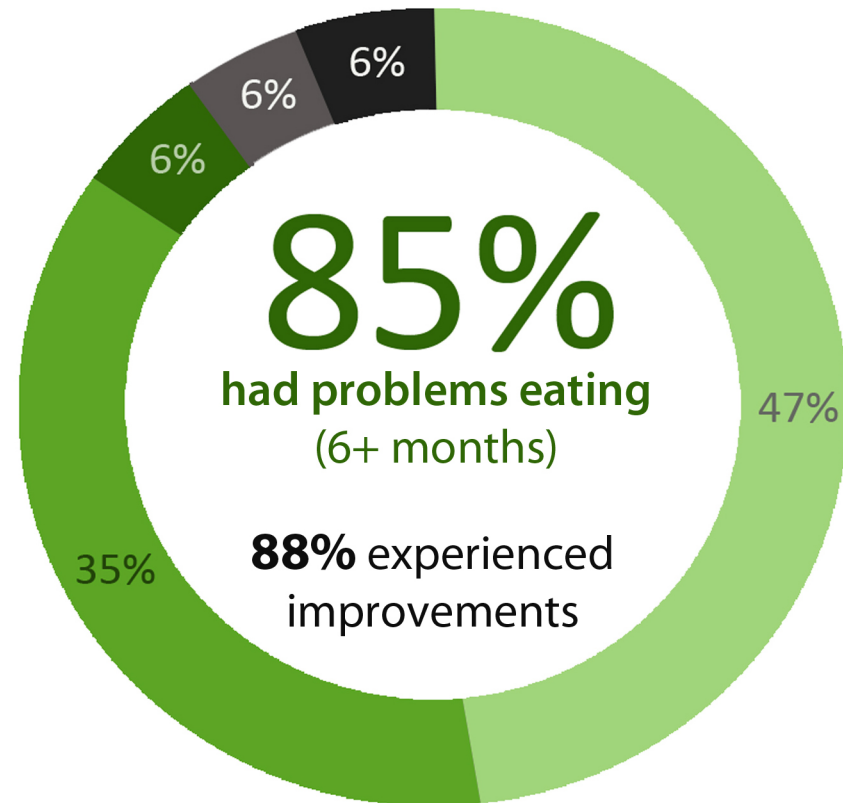
“When we nursed for the first time, two hours after the release, I cried tears of joy. No pain, no clicking sounds and no excessive vomitting after the feeding. Just a happy and sleepy baby. Before he would throw up for hours after every feeding.”  
(4 months at release)



# QUESTION: Have the problems improved upon the release of PTT?

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- Unsure
- Worsening of symptoms

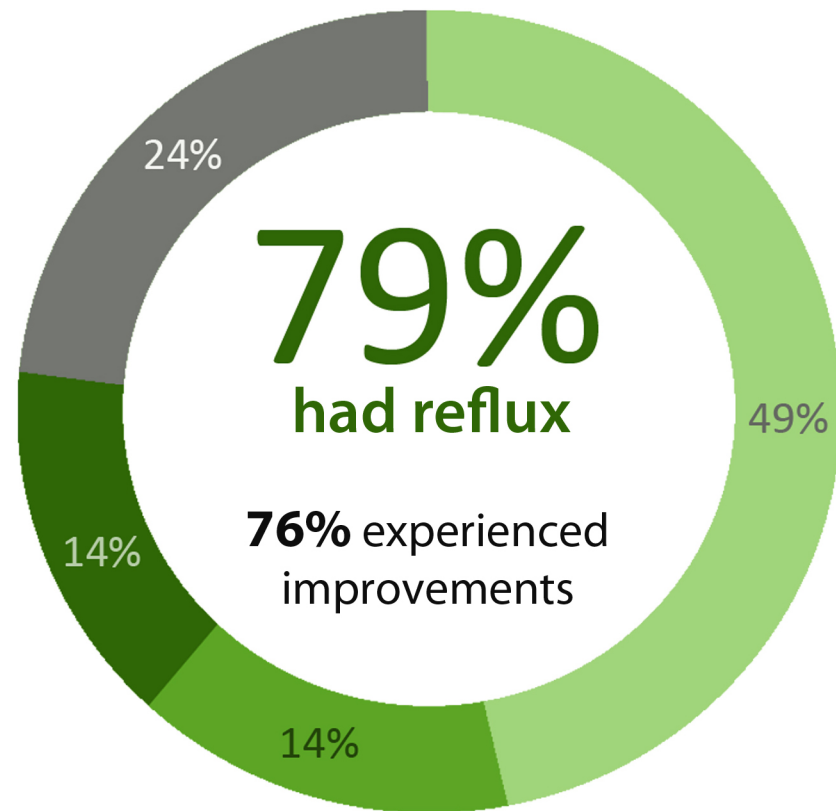
“The best thing about this release is that she now, for the first time ever, is able to eat something other than liquid foods.”  
(1 year at release)



## QUESTION: Have the problems improved upon the release of PTT?



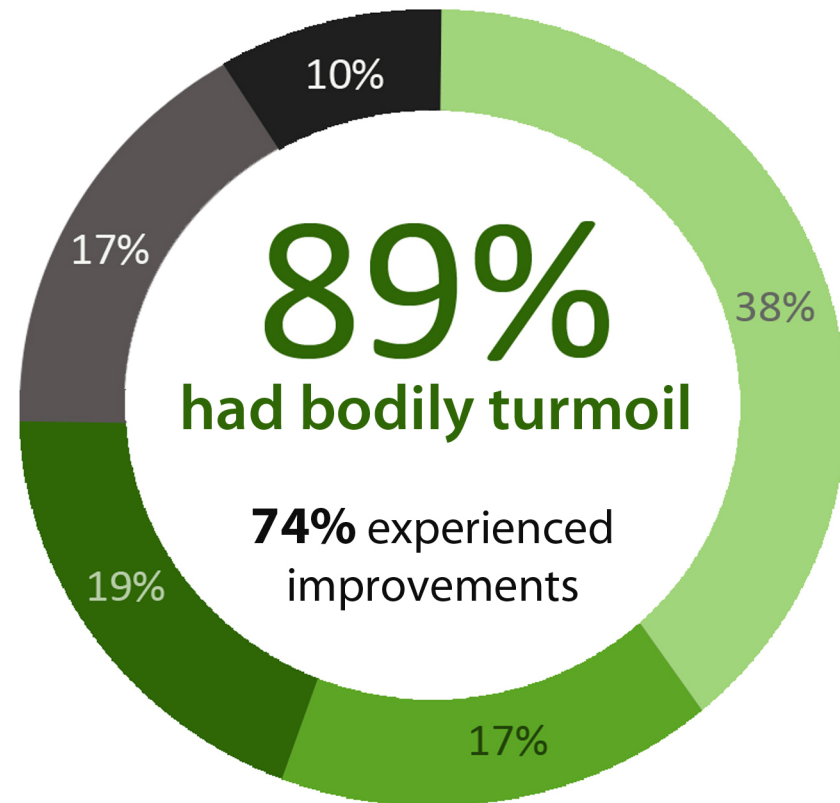
“He doesn’t have reflux anymore, we are seeing a boy who’s happy and is speaking. He can eat anything now, except milk and soy. Having the PTT release is the best decision I’ve made in this whole reflux hell!”  
(14 months at release)



# QUESTION: Have the problems improved upon the release of PTT?

- Immediat improvement
- Improvement within a month
- Improvement after one month
- No change of symptoms
- Unsure
- Worsening of symptoms

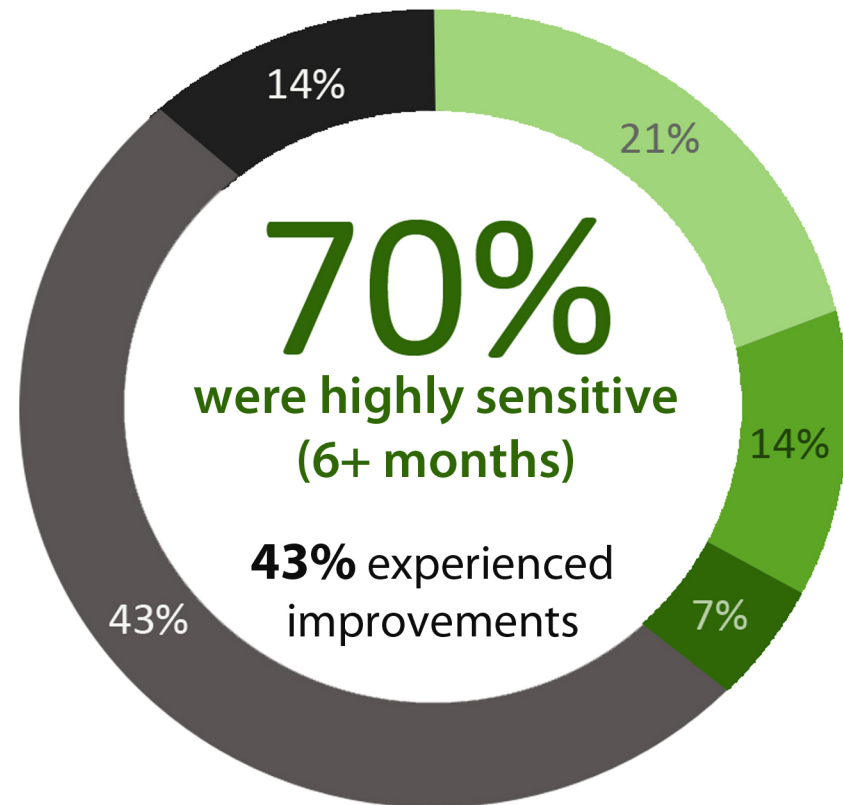
“We have got a completely different boy upon the PTT release. From one day to the next! He is more mentally stabile, more calm, has fewer meltdowns and can play on his own sometimes. We never saw these things before.”  
(22 months at release)



## QUESTION: Have the problems improved upon the release of PTT?



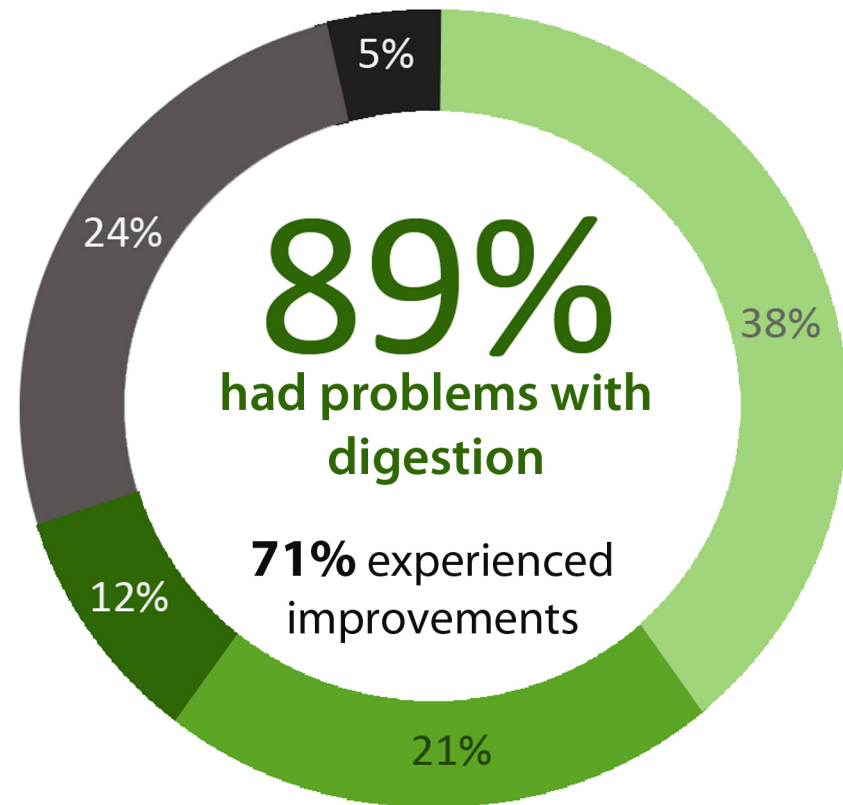
“He couldn’t stand being close to anyone or to hug and cuddle. It was like as if he was in pain from doing it. After the release he has become this entirely different person. He now enjoys to sit close to someone and read a book, he is very affectionate and often wants to lie on top of us when he wants to relax.”  
(2,5 years at release)



# QUESTION: Have the problems improved upon the release of PTT?

- Immediate improvement
- Improvement within a month
- Improvement after one month
- No change of symptoms
- Unsure
- Worsening of symptoms

“From day one upon the release we saw no more green stools. Before the PTT-release there were green stools almost every time.”  
(4 months at release)



# QUESTION: Have the problems improved upon the release of PTT?

- Immediat improvement
- Improvement within a month
- Improvement after one month
- No change of symptoms
- Unsure
- Worsening of symptoms

“Sleeping has gone from being a total of 3-6 hours with 3-15 awakenings to being - from the first day after the release - a total of 11 hours straight with no awakenings.”  
(22 months at release)





# Thoughts upon the PTT-release

## QUESTION: What has been the BEST thing about getting the release?

"That our daughter is "back". As a parent you are aware of when your child isn't feeling as well as she is supposed to. Now she is, and that will save every mother from being stressed out."

(4 months at release)

"Everything, my life has changed completely. To be able to go for a walk with the stroller without my baby crying after 5 minutes."

(3 months at release)

That he is now able to swallow his food without feeling like he's about to choke or feeling the need to spit it all out. Everything else is just a bonus on top of that. He sleeps better, doesn't need to breastfeed as often and has better digestion."

(11 months at release)

"An immediately happier baby. And that I'm not as cuckoo headed as all the doctors told me I was."

(3 months at release)

"His language development and eating skills have taken a quantum leap after the release, which is to say his oral motor skills have improved significantly. Before the release he used 2-3 sounds (not a single word). Two weeks upon the release he tried naming all the colours. Furthermore his gross motor skills have majorly improved."

(20 months at release)

"Her rapid development! We are astonished and happy for the girl we have now. I can finally say she is thriving 100%"

(6 months at release)

# Thoughts upon the PTT-release

## QUESTION: What has been the WORST thing about getting the release?

"To inflict pain and anxiety on him. And all of our countless discussions about whether or not to get the release and whether or not it would work."

(7,5 months at release)

"The smell of burned flesh and that we hadn't prepared him well enough for the numbness in his tongue, which scared him. We had to be very persuasive for him to even open his mouth."

(4,5 years at release)

"People are being very critical towards what we have done to our child. They will say things like "We will never know if the betterings are actually linked to the tongue tie release." It is tough having to keep insisting on the things we see so very clearly linked. It has resulted in a reaction in us parents that might likely be a form of PTSD. "

(4 months at release)

"Having to make the decision about seeking medical help in another country. And the procedure in itself."

(3,5 years at release)

"The scream that she cried out during the procedure and that she cried for a long time afterwards. It was very hard on her. The attempts to get into her mouth to do aftercare and the pulling of her tongue."

(2 years at release)

"That noone have listened to me when I insisted that something was wrong. That was the worst part of this whole thing. The worst thing about the procedure was that we had to go abroad to get help - with a 3 month old baby. That was a hard decision to make."

(3 months at release)

"Absolutely nothing."

(4,5 years at release)

# Thoughts upon the PTT-release

**QUESTION:** Did you regret getting your child released?



"I regret the way it was done, but he needed to have his tie released, and in the long run I'm sure it will help him. But getting a tongue tie release isn't something you "just" do. I think it's important to stress that out. It brings with it some mental risks that we certainly weren't prepared for.

(undecided)

# PTT can make breastfeeding difficult

A lucky few succeeded in breastfeeding their tongue tied baby without problems, but for the majority it was very challenging.



4%

breastfed for at least  
6 months without  
any problems



45%

breastfed for at least  
6 months, but with  
difficulties



49%

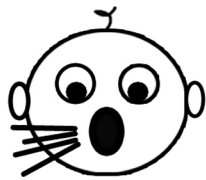
had to unwillingly give up  
breastfeeding within the  
first 6 months

(the remaining 2% have answered that the child was never breastfed)

# Danish health care providers misdiagnose PTT

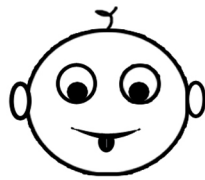
In Denmark there are no general guidelines for when to release a short frenulum (tongue tie). The most common ways for doctors to diagnose a tongue tie is to look to see if the tongue has a heart shape, if the baby can get the tongue past the lips or if there occurs speech problems later in life that can't be solved through speech therapy.

50%



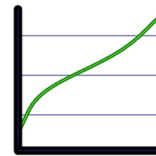
had problems with speech  
(6+ months)

60%



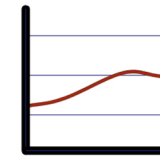
could stick out  
their tongue

60%



had no  
weight problems

33%



had problems putting  
on or maintaining weight  
(0-6 months)

# Danish health care providers misdiagnose PTT

**85%**

have had an evaluation by at least one health care provider, who didn't find a release of the frenulum to be relevant.

**21%**

of the children had their frenulum cut by a Danish ENT prior to the PTT release in The Netherlands.

# Danish health care providers misdiagnose PTT

## 40 out of 47

have experienced one or more health care provider(s) saying a release of the frenulum wasn't necessary.

- The 40 children (85% of the total amount) were most commonly rejected by an ENT
- Some children were rejected by up to 4 different ENTs
- More than half of the children were told that a release wasn't necessary by their health care nurse, who is one of the first providers to examine the baby

ENT doctor 68%

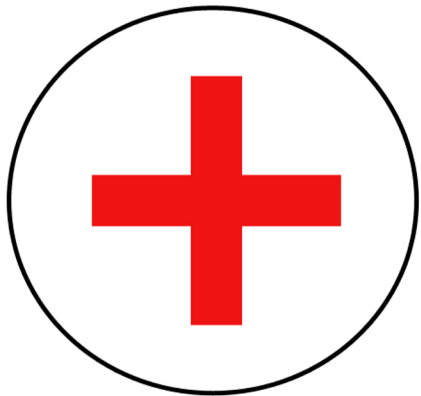
Health care nurse 58%

General practitioner 45%

Midwife 43%

Pediatrician 33%

# Danish health care providers misdiagnose PTT



**60%** of the children were reinstated at the hospital after being discharged after birth.

- Half of these children were hospitalized for more than 5 days
- The average time of hospitalization was 6 days
- In this average isn't included three cases who had been admitted significantly longer than the rest. They stayed at the hospital for 70, 150 and 270 days.



## This is how we collected the data...

- The study covers minimum 50% of the total number of Danish children treated for PTT - all diagnosed and treated by Kirsten Slagter, DDS, PhD, Dentist, Implantologist, Tongriem Clinic, Groningen, Holland.
- A total of 103 persons of all ages had a frenectomy done by Dr. Kirsten Slagter in 2017, out of these were at least 8 adults.
- The purpose of this material is to create the transparency of the experienced impact of the PTT release for these 47 children. The purpose is *not* to convince any parents to opt for a PTT release. Data was collected in January 2018 via an extensive questionnaire with +60 questions answered by the parents.
- 43 families, who had one or more children diagnosed with PTT, participated in the survey.
- With some questions the parents was given the option to further clarify the answers given by multiple choice, which has resulted in both qualitative and quantitative findings.
- 46% of the patients had the procedure done in November or December 2017.
- All replies are 100% subjective and concrete answers by the parents. The parents assessed the challenges at time of the PTT release and the changes after the release, i.e. whether improvement was instant, within 1 month or after 1 month, or if the challenges remained unchanged or even worsened after the PTT release
- Findings in this study may not be representative for the wider population.

The survey was conducted by occupational therapist Ulla Lebahn in addition to Symposium 2018, which is themed around mouth-based problems leading to dental issues, speech difficulties, failure to thrive and/or feeding and eating difficulties  
More information available at:

[www.lebahn.dk](http://www.lebahn.dk)