Compilation of Clubfoot Items, Questions and Red Flags

Created by Natalya Schluechter - mom of two wonderful girls
https://www.nosurgery4clubfoot.com/cheatsheet

Dear Mamas, Papas, Parents, Grandparents, Caretakers, Friends,
So much on this journey is unknown to you, for now – but soon you will be an expert. I remember standing alone in the hospital with a mask on my face, two hot salty waterfalls streaming down my cheeks, apologizing for crying because I wanted so badly to be strong. My baby girl was one week old and surrounded by four people, the word "severe" being uttered over and over, beating up my heart in ways I can't explain. **Severe**. I was unprepared, postpartum, standing there all alone – thank you, covid. Every week a different doctor applied the cast, with barely any explanation on the process. Luckily, they didn't make her feet complex, though very rare 'residual' features remained. A second opinion with a Top 15 doctor (linked on Page 7) confirmed that her feet were corrected, but it could have gone a whole different way.
So I became determined to compile an epic list to support others. Today my girl is 19 months old and running around after her big sister, and has reached all the milestones she was supposed to on time!
It is overwhelming, but the advice in this "cheat sheet" for lack of a better word, is based on research articles, advice from other parents, and the professional opinions of top orthopedists. If you have questions, concerns, or difficulties on the journey, please feel welcome to reach out to me.
Do remember, we have all gone through similar steps of the journey, you are not the first, and you aren't alone.
There are two things in your control: 1. finding an experienced doctor 2. bracing to lower relapse risk.
Page 7 links you to a ***huge*** list of doctors globally + of highly skilled doctors for complex cases. Take things one day at a time, one hour at a time, and when things are truly overwhelming, five minutes at a time.
Take *lots* of photos, give *lots* of cuddles, get them to laugh – be your baby's rock and their number one advocate – ***be the voice they do not yet have.*** Trust your instincts, but be open to advice because we are also taking care to support others with our stories and experiences.
You've got this!

Course of the Ponseti Treatment (A Sample Schedule)
Birth
1 Week Old – Cast #1
2 Weeks Old – Cast #2
3 Weeks Old – Cast #3
4 Weeks Old – Cast #4
5 Weeks Old – Cast #5
6 Weeks Old – Cast #6
7 Weeks Old Tenotomy + Tenotomy Cast (stays on for 3 weeks)*
10 Weeks Old – Tenotomy Cast Removed, BnB (Boots and Bar) Introduced
23h wear for 3 months (first week of adjustment is very difficult – do not remove BnB except for the 1h!)
5.5 Months Old – 23h wear Graduation! – reduction to 20 hours --child learning to sit/crawl
7.5 Months Old – 18h wear introduced --child learning to sit/crawl
9.5 Months Old – 16h wear introduced --child learning to pull up
1st Birthday – 12 to 14h wear **until 5th birthday** (*stay closer to 14h*) --child learning to walk

Clubfoot Terminology:
BnB: Boots and Bar
Abduction: foot turning outward
Dorsiflexion: foot flexing up (skyward)
BCF/LCF/RCF: Bilateral/Left/Right Club Foot
Tenotomy: *see below
ATTT: Anterior tibialis tendon transfer

The gradual reduction schedule allows your child to learn the skills all other children are learning, and they can also learn to do these things with the BnB on, they are not hindered in any way! However, it is perfectly normal for a clubfoot child to be a couple months delayed with crawling/walking milestones, though my daughter has been well ahead of schedule right now – flipped back to tummy at 3.5mos; crawled at 6mos, pulled up at 8.5mos, cruised furniture at 10mos, stood up at 12mos and walked unassisted 5-6 steps at 12.5mos.

***Tenotomy:** *90%* of clubfoot children will have a tenotomy surgery (it isn't full-on surgery) – it is as simple as cutting a tongue tie and leaves a tiny scar on the back of the leg. The doctor uses a scalpel to make a small puncture in the back of the foot, cutting the Achilles tendon. The Achilles tendon is lengthened, thus improving flexibility of the ankle. No stitches are required. The final cast is then applied for 3 weeks. Tenotomy can be done either in the clinic with local anesthesia (much like a tooth cavity) or in the operating theater with general anesthesia. When worrying which is better, there are pros and cons to both. While Dr Ponseti performed tenotomies in the normal clinic room and the child could go home immediately, sometimes children can be quite active and today's doctors are opting for the operating room – sterile conditions and a baby that is sedated and not kicking like crazy. We had partial sedation and it was very hard on her stomach – diarrhea for weeks, but I wouldn't change how we did it.

Updated: September 2023 by Natalya Schluechter

Studies on Clubfeet (Scholarly Articles Included)

Your Casting Appointment: What to Bring
Diaper Blowouts (*oh no!)*
Sponge Baths in Casts
Vaccinations
Sleep Sacks
BnB (Boots and Bar) Brands (Foot Abduction Braces (FABs))
Blisters/Pressure Sores
  Pressure Saddles
  Bunions
Socks (for BnB)
Clothing (for BnB)
Shoes
Baby Carriers (with casting/with BnB)
BnB Covers
Head Support for Sleep
High Chairs
Books + Accessories
Walkers/Bouncers/Saucers/Pikler Triangle
Baby Cranky All of the Sudden with BnB
Car Seats & Strollers

Red Light Green Light List of Doctors
Doctors Who Can Manipulate Complex Feet

Relapses & Bracing
BnB Angles
BnB Angles for Complex Clubfoot
Gradual Reduction of Hours
Stretches
Casting Questions to Ask Your Doctor
BnB Questions to Ask Your Doctor
Red Flags

!!!FIRST WEEK OF BOOTS AND BAR!!!
What to Expect After a Relapse
ATTT Surgery – Tendon Transfer

Take **lots of photos between cast changes, especially the ***soles*** of the feet. Documenting whether your child had a crease *at birth* is important, because any doctor who may later say a foot is *atypical* when there was no crease at birth to begin with are suspect (a red flag). If your child is born with atypical feet, as my girl was – please consider taking the time to look for a doctor specialized in atypical/complex feet, there are very few in the world that are so skilled (link in questions below).
**Always take a photo of how the feet look when leaving the casting appointment in case the feet slip in the cast + mark location of toes with a permanent marker.
**Starting casting early isn't indicative of the best success. In fact, waiting one month can yield better results. But, starting early means being in BnB earlier, and getting through the 3 month 23-hour wear period faster, when baby isn't as "strong" and "active". This also means your child can be on their way to meeting milestones just a bit sooner.

Your Casting Appointments
Castings typically take ~15 minutes for cast removal and ~15 minutes per leg.
- Bottle of Milk
- Cherry-pit pillow to microwave & keep casts warm in the first 24 hours
- Extra Diaper
- Extra Onesie, castings can get wet!
- Pacifier
- Sugar Water is sometimes offered to calm the baby
- White Noise (my girl calms with it immediately, the doctors and nurses were impressed!)
- *Roll a towel to elevate the legs when baby is napping/sleeping

Diaper Blowouts (*oh no!*)
- Long Panty Liners (prevention)
- Leg Warmers (prevention)
- Cut toes of sock and use like a leg warmer (prevention)
- Cotton Roll + Coban Roll (*after blowout* pad ½ into cast, secure w/ Coban)
- Cotton Roll + Medical Tape (*after blowout)

Sponge Baths in Casts
Babies are clean – they don't run or jump or play in the dirt yet. The dirtiest they will get is inside the diaper, so a sponge bath is relatively simple. Wet a washcloth in warm water (I didn't even use soap!), rinse, wipe down baby, repeat. Easy!
- Amazon Basics Washcloths Pack of 24 (inexpensive, easy to throw in the washing machine)
- Warm bucket of water

Vaccinations
A baby in casts can be vaccinated, there's no reason to hold off vaccinations. Vaccinations can be done into the upper thigh or the arm. A suggestion is to get the chicken pox vaccination.

Bracing During Sickness
You do not need to remove the brace during sickness. It's a slippery slope if you imagine every sniffle or fever means the brace needs to be off - you remove it for one night, but the next night your child still has a fever so it's one more night, and…off we go taking the brace off regularly. They are sick, they are fussy, they have a fever, and they are unhappy, but it's not about the brace, it's about the discomfort of being sick. The child does not think wearing the brace when sick is added discomfort, we think that as parents. **Removing the brace could actually cause more issues (i.e. rejection of the brace or relapse).** We brace through fevers (39.2 (102.5) was the highest we had), diarrhea, vomiting, etc. Sicknesses where brace removal may be needed (continue bracing unless truly severe discomfort): Hand Foot & Mouth Disease or Chicken Pox

Sleep Sacks

Aden + Anais	Merlin Sleepsuit
Dreamland Weighted	Nested Bean
GroBag	Slumbersack (up to size 6-10 years!)
Halo – top recommendation	Zipadee Zip

BnB (Boots and Bar) Brands (Foot Abduction Braces (FABs))

BnB hold the corrected feet in place during a child's growth and more importantly, growth spurts (my girl's foot grew half a centimeter in a week visibly!). If the boots aren't put on correctly and ***very*** *tightly*, you are risking not only relapse but also blisters and pressure sores.

- **Mitchell Boots** https://mdorthopaedics.com
  - Ponseti Bar (340 grams for bar + size 00 boots; bar is adjustable, aluminum)
    - If you lose a main screw, ask for a "stainless steel countersunk machine screw"
  - Dobbs Bar
    - Model SDCBMD (6months and older usually [because it is heavy]) https://www.dobbsbrace.com/sdcbmd
    - Model SDCBMD 2.0 (1y and older) https://www.dobbsbrace.com/sdcbmd2
    - Easy Click Model EZCLKMD https://www.dobbsbrace.com/ezclkmd
- **Markell Shoes** https://markellshoe.com
  Markell Boots Tips PDF
  - Dennis Brown Bar (DBB) (typically adjustable bar is rare)
    - Most common are the Fillauer Gold fixed length or Red Adjustable Bar, although other bars are available

  https://markellshoe.com/open-toe-boots-and-bars.pdf
  - Dobbs Bar
    - Dobbs Dynamic Bar model QDCB https://www.dobbsbrace.com/qdcb (6 months and up)
    - Dobbs Easy Click Model EZCLK

  https://www.dobbsbrace.com/ezclk
- **Iowa Brace (+Flexbar) + Iowa Boots** (bar is not adjustable, plastic bars)
  - Flexbar (Clubfoot Solutions)
  - Dobbs
    - Iowa Dobbs Bar Model IADCB (6 months and older) https://www.dobbsbrace.com/store/IADCB-p411112199
    - Iowa Dobbs Bar 2.0 (1year and older) Model IADCB2.0 https://www.dobbsbrace.com/store/IADCB-2-0-p246266944
    - Dobbs Easy Click Model EZCLKI https://www.dobbsbrace.com/store/EZCLKI-p411146295
- **Alfa Flex Bar + Comfoot Boots** (Germany) we had it in the beginning & switched to Mitchell
- **C-Pro Direct BnB** (bars not adjustable, all bars sent with initial order)
  (hole in heel makes it difficult to check compliance)
  https://c-prodirect.com/boots-and-bar-system

Blisters/Pressure Sores

****Blisters form due to friction – make those boots tight so there is no movement inside!**

****Creams before putting on socks, while a good intention, can cause blisters (exceptions: Foot Glide/Compeed Stick).**

Putting on BnB Video *** IMPORTANT* please follow these techniques**

Putting on BnB Instructions *** IMPORTANT* please follow these techniques**

Aquaphor

Compeed Anti-blister Stick

Compeed Blister Bandaids

DuoDerm – cut 1-2cm larger than the sore (round, no corners!), allow to fall off on its own

FootGlide Anti-blister Balm

Talc Baby Powder in Socks

Moleskin - put a layer or two (or three) on the inner heal of the boots will help prevent blisters.

Sheepskin from tandy leather – stitch to strap at a shoe repair shop

Pressure Saddles (use sparingly as they can potentially affect dorsiflexion) USA Europe (Poland)

1. When used, the middle strap can be too loose, causing the foot not to be placed well in boot.
2. The pressure saddle is stiff and is placed on the dorsal side of the foot, exactly where the foot flexes up. When something is on the dorsal side, it limits the foot movement "up".

Round cotton make-up sponges can be used as an alternative to pressure saddles.

Blisters/Pressure Sores on Non-Clubfoot

Heel Pads can help to keep the heel off the back of the boot, thus preventing blistering.

Bunions

Sometimes children will develop bunions from the boot buckle. You can take the boots to a shoe repair shop and have them stitch the buckles in lieu of the buckles.

Breaking in New Boots + Being "in-between holes"

When starting a new pair of boots, follow these steps:

1. Wash the boots (Mitchell) in the washing machine in a delicates bag or pillow case with a large towel or two thrown in. Air dry for one day. You can do this twice if you have the days to do so.
2. Wear the "new" boots during naps only for a week to let the material stretch further and not burden the foot with wearing new boots too much. Wear the "old" boots during night time sleep.
3. Watch out for the "in-between holes" period, you will always find yourself having to go to the next hole for a better fit after a week or two.

About 10-14 days after wearing a new pair of boots, the holes you were using on the middle strap will become too loose for a good tight fit. However, the next hole is too tight. This is what I call being *"in-between" holes*. You want to use a pressure saddle for a couple of days to take away the pressure from the top of the foot and to stretch the material a bit.

Bar Width

For adjustable bars like the Ponseti and Dobbs bar, an Allen Key can be used to adjust the bar. Some children prefer a bar that is a little wider than the shoulders.

Chances of Clubfoot in Siblings

Having one child with clubfoot sets the likelihood that another child will have clubfoot as 1 in 30.

Socks (for BnB)

- I recommend having 6 pairs of any one size
- Avoid thick/fuzzy socks - hinder getting heel flat, can cause extra sweating + athlete's foot
- Choose lighter colors so you can see the heel more clearly in the hole
- Socks aren't the most important aspect of successful BnB, ***properly tightening the boots*** is

Black Robin Single/Double Layer Europe (Poland) UK USA
(Double Layer recommended for 23 hour wear to avoid friction, aka blisters!)
Smart Knit (seamless) UK USA
AFO Socks USA
Anole USA
Baba Mate
Carters Triple Roll
Cat and Jack from Target
Gap Triple Roll USA
H&M Triple Roll
Hudson USA
Tights
QandSweat

Clothing (for BnB)

Sleepsuits
- Carters
- Cat & Jack
- Hudson – top recommendation
- Kickee Pants
- Next (my **favorite**)
- Patpat (decent, cheap, don't wash well)
- Petit Bateau

BnB Covers

(Russia-based) Instagram: dalexia_hm
(Philippines-based) Love, Athalia
(Canada-based) While They Were Asleep
(UK-based) Happy Footers
(UK-based) Boots and Bar
26th Avenue Clubfoot Essentials
Blue Belle KC
Clubfoot Cozies

High Chairs

Abbie Beyond High Chair
Graco Slim Snacker
Graco Table to Table 7 in 1
Ingenuity (what we have)
Upseat

Baby Carriers (with casting/with BnB)

Baby Bjorn
Beco Gemini (recommended by Dr Dobbs)
Bebamour (used by us)
Boba Wrap
Cuddle Bug Wrap
Ergo Baby Embrace
Ergo Baby Omni 360 – Top BnB Recommendation
KTan Wrap
Infantino 4 in 1 – Top BnB Recommendation
Lillebaby All Seasons – Top BnB Recommendation
Omni 360 Mesh
Ring Slings
Tula Free to Grow

Head Support for Sleep

Koala USA – used by us for a perfect round baby head

Shoes

Barefoot is best, followed by grippy socks, then soft-soles leather moccasins (roughly 20$ a pair).

*For those with different sized feet in the US, Zappos and Nordstrom are companies that sell different-sized shoes.
Zappos Single Shoes Community
Nordstrom Split Shoe Services

Books

The Parents' Guide to Clubfoot
1 in 1000
Pete's Neat Feet
For more books and bar covers, and other cool stuff for clubfoot families:
https://nosurgery4clubfoot.com/stuff

Walkers/Bouncers/Saucers/Pikler Triangle

Many doctors say ***no*** to bouncers/saucers and even walkers because the foot can plantar-flex or the child uses their tippy toes rather than the full foot.

In 2018, the American Academy of Pediatrics called for all infant walkers to be *banned.* The AAP says they don't help children learn how to walk, and in contrast, can actually delay when a child starts to walk because the movements they use to move a walker around doesn't translate to the movements needed to walk independently, and the children can't see their feet and legs.

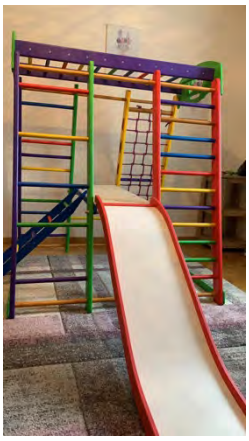
The overall message from experts is that jumping devices are okay as long as they are not used for more than a short period of time (15 minutes) and they are freestanding, not attached to doorways.

In the grand scheme of things, 15 minutes is really not much time at all and can easily be filled by another activity.

Things to consider purchasing instead:

Pikler Triangle with Ramp. Best if it is foldable and over 80 cm tall as it will grow with your child.

Indoor Gym/Playground. We have one (photo) and are lucky to be using it with our second girl now – best 330 euro investment for what is going on 4 years of fun (especially in winter). We read under it, play camping, climb, jump, slide!



Baby Cranky All of the Sudden with BnB

You feel like your child is suddenly rejecting BnB completely, kicking their feet like crazy, crying, waking frequently or fighting sleep.

1. Check that the bar is the correct length, sometimes we completely forget to check bar width.
2. Check for signs of relapse.

Car Seats & Strollers

These items are best to be selected in-store whenever possible. Recommending which car seat would work is difficult as car seat brands vary internationally, as do international standards. Every car is different, one car seat could easily fit into a large car but would be pressed in a smaller car. And, if a family has several children, the fit in the entire back seat is called into question. Also, as outlined in the next section, only the first year of life is of true consideration, as is wearing BnB in the car seat.

Wearing BnB during car rides is a controversial topic in the clubfoot community. A lot of doctors are torn on whether to allow it on car rides – some say yes, others to keep boots on, others no. Why?

1. There are a few known cases when car accidents have caused broken legs due to baby wearing a brace in the car seat.
   Rule of thumb can be: are the child's feet touching the seat of the car?
2. It depends on your car travel timings and how your child behaves in the car.

a. Are you frequently on the road? – consider not risking it, take the bar off
- For long stretches? – consider keeping it off
- Just to the supermarket? – keep it on

b. Does your child take long naps in the car? It's your risk. Remember, a child with their muscles at rest risks relapse, which is why we wear BnB during sleep.
   Also, remember that during the first year you're bracing for long hours but after the first birthday this will mainly be night-time only with a long afternoon nap, so the consideration is really mostly for the first year of life regarding wearing the brace in the car.

Red Light Green Light List of Doctors
Doctors Who Can Manipulate Complex Feet

Relapses and Bracing for Children Treated with Ponseti Method
(approved by Dr Jose A Morcuende)
Relapses are a common occurrence among children with clubfoot up to the age of six years. The following is the rate of relapse for discontinuing brace-wearing at the age designated:

- 1st year 90%
- 2nd year 70-80%
- 3rd year 30-40%
- 4th year 10-15%
- 5th year+ ~6%

Severity of clubfoot deformity at birth is not a reliable indicator of the odds of relapse, therefore almost all clubfoot patients are held to the same bracing protocols in order to provide them with the best protection against relapse.
Article: Bracing in clubfoot: do we know enough?:
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6598043/

Gradual Reduction of Hours
Removal of Final Cast + Introduction of BnB

- 23 hours for 3 months (typically begins at ~3 months of age)
- 20 hours for 2 months (typically begins at ~6 months of age)
- 18 hours for 2 months (typically begins at ~8 months of age)
- 16 hours for 2 months (typically begins at ~10 months of age)
- Graduation to 12-14 hours ~first birthday

Why gradual reduction?

- Babies do not like sharp transitions or changes to routines. Dropping to naps/night time can lead to brace rejection and sleep problems.
- If for 3 months it was critical to brace 23h and not allow for more time without the brace, why is it suddenly alright to decrease to 12h?
- Because the relapse risk is at a staggering 90% in the first year.
- It allows for a good mix between time in the brace and active time without it.

Reduction of hours per Dr Morcuende (tied to nap time averages per month of age):
"I advise to use brace full time for 3 months, followed by 14-16 hours for 3 months. By this age (7-8 months old) the baby starts to sit and even crawl some, so it is best to let them develop and use the brace only at night for 12-14 hours. When they walk independently around 14 -16 months, they use it for 12 hours until 4-5 years old."

Why is wearing BnB during naps important?
Babies fall asleep hard and deep very quickly. Deep sleep makes the whole body relax: it is not active – muscles, tendons and ligaments do not work because they are not set in motion by the brain. Due to "muscle memory" each relaxation of the foot during sleep requires the use of a brace, even when the child sleeps 10 minutes.

Relapse
If your child relapses, the entire process of clubfoot management ***repeats*** – yes, imagine a few weeks of casting, possibly a repeat tenotomy and more long hours of bracing. This is why properly adhering to the BnB hours is important and especially going through **gradual reduction** in the first year, as it reduces the risk of relapse.

23-hour wear for a baby with gradual reduction in the first year is much easier to do than risking a relapse and the same for a toddler who has learned to walk.

100% parental adherence to bracing protocol does not mean your child will 100% not relapse, but it decreases the odds of relapse drastically.

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BnB Angles
Corrected clubfoot: 60 - 70 degrees abduction
Unaffected foot: 30 - 40 degrees.
(The last cast applied to a corrected clubfoot should have been rotated to 60 - 70 degrees unless complex)

Complex Clubfoot Angles
If the child has been diagnosed with atypical (at birth) or complex (improper casting) clubfoot, the boot for the corrected clubfoot should be set to 20 - 30 degrees and worked up to 40 - 50 degrees. In general, BnB angles are to be set to the same angle as the final cast abduction.

These articles discuss abduction degrees and treatment of complex clubfoot in great detail, including the method for doing so, which differs from that of treating regular clubfoot:
https://www.clubfootcares.org/atypical-complex-clubfoot
https://www.mdorthopaedics.com/.../10/complex-proofs.pdf

This article goes into specific detail as to why:
"This type of clubfoot is difficult to treat and requires modification of standard Ponseti technique. Adduction of forefeet should not be corrected beyond 40 degrees to prevent hyperabduction at tarso-metatarsal joint."
http://www.journalijar.com/uploads/356_IJAR-6592.pdf

Stretches
Following the traditional Ponseti method, stretches are *not necessary* – the child naturally stretches the foot through bracing, walking, playing and daily activities. Do choose floor play at home over a long walk in the stroller outside whenever possible to activate those muscles!
Of course, stretches can only positively impact your child, but they should be pleasant and not bring stress, discomfort, pain, or tears. Here are some links to stretching material:

https://paleyinstitute.org/wp-content/uploads/2020-08-24-2-1200x740.jpg?fbclid=IwAR3JRN623QaK-AdqrqNHI25hfWEp8w6LCVD55BmaopYniId6A91ePGCcSX4

https://paleyinstitute.org/wp-content/uploads/2020-08-24-2-1200x740.jpg

https://www.youtube.com/watch?v=sF9AupChJhs

https://www.youtube.com/watch?v=AfXcpsS8mqw

Passing on Your Boots
USA braceclubfootorg.com
Worldwide
STEPS Charity https://www.stepsworldwide.org/
Please send used medical equipment (boots and bars, pavlik harnesses, prosthesis...):
LIMB-art Ltd
Nant-y-Lladron
Bylchau
Conwy
LL16 5SN
Wales
United Kingdom

Casting Questions for Your Doctor credit: Kori Rush
Ask some seemingly *hard* questions. Don't feel nervous about asking these things, and don't worry about taking the doctor's time. If they can't answer these questions without much thought, there is a problem.

- Ask about your doctor's experience. How long have they been using the Ponseti Method? How long have they treated clubfoot, how many clubfeet have they successfully treated, who trained them and what had that training entailed. Ask if they were trained by Ponseti International or some other source, and who was that trainer trained by? You're looking for someone in their background who was actually trained by a Ponseti Method expert.
- Ask about casting material - should be plaster, unless they are amongst the elite skilled with fiberglass.
- Ask how often their casts slip and what they do about it. Slipped casts are **always** the fault of the doctor, not an "active" child or the parent carrying the child a certain way, or sitting in a car seat. Slipped casts should be removed ASAP to avoid complex deformities that would require an elite set of hands to fix (we currently know of 15 doctors that skilled globally) (rocker bottom, midfoot deformity, etc). If you have even the thought that the cast has slipped, remove immediately.
- Ask the average number of casts they use (5-7 is norm), when they take each cast off (should be weekly, except for tenotomy cast which is 3 weeks) and how it's removed (should be right before the next cast, a few hours maximum, not the night before – as per Dr Dobbs the feet can stiffen quickly).
- Ask which brace they prescribe and how that's done (when are feet measured, who is the orthotist shop, etc). Ask for contact details in case adjustments are needed, or if something breaks.
- Ask what their bracing schedule is (gradual reduction or sudden drop to 12hr? How many years?)
  You're looking for **gradual reduction** during the first year, bracing for 5 years and not any less.
  Most importantly ask what is their overall success rate.
- What is their ATTT (anterior tibialus tendon transfer rate)?
  ATTT is a procedure used to treat recurrent clubfoot. You're looking for percentages there. How many surgeries they do and when, at what age? (answer should be: after all casting and bracing options have been exhausted, only then is ATTT considered after age 4).
- What is their approach for relapse? Casting/repeat tenotomy/23-h wear?
- You need to find out what you want to hear from these questions. What relapse rate is ok with you? Do you agree that your doctor should be Ponseti trained, or is it ok that random people did the doctor's training? Do you think plaster casts are essential? Are you concerned about modifications to the Ponseti Method such as bracing schedule modifications or do you want to follow all of the statistics/studies and really give the best chances for your child?

Knowing enough about what you are willing to accept helps when you formulate these questions and analyze the answers you're given. Some deep research into the Ponseti Method might be helpful for your own comfort.

BnB Questions for Your Doctor
- Best way to contact them (bruising, blisters, pressure sores, etc.)?
- What is the doctor's on-call policy?
- Is there a doctor you can talk to on weekends/off hours and this doctor's expertise?
- What will the reduction of hours look like (wear policy)? You want **gradual reduction**
- Should I remove the BnB for car rides?
- How long will this pair of boots last us until we need the next pair?
- How do I order the next pair of boots, how long does ordering take?
- How often should we have check-ups/meetings with you?
- Advice on walkers/gliders/bouncers?

RED FLAGS

Casting

- Feet slipping inside casts are *always* the fault of the doctor. This can cause complex feet. If a cast slips – remove the cast *immediately.* Don't second guess this. No cast is better than a slipped cast!
  Many doctors are blaming strong, willful or older babies on cast slips.
  One cast slip here and there is ok, two or more are really big red flags.
- Casting material should be plaster. Fiberglass, which sounds like "stronger" material, is not traditional for the Ponseti Method is incredibly difficult to work with. Fiberglass is less heavy and slips more often.
- Excessive casting. The Ponseti Method typically has 4-6 casts.
- Toes that overlap in the casts. If the doctor says this is "ok", don't be afraid to ask if the doctor's own toes are currently overlapping in their shoes.
- Casts not bent to 90 degrees at the knee.
- Casts that are not reaching the upper thigh – half-leg casts are not ok.
- Cast removal should be maximum a couple hours before the next cast is placed, not the day/night before. "Feet tighten up quickly." – Dr Dobbs.
- Curvature of the feet after casting. When looking at the bottom of the foot, the sides of the foot should be straight.
- Hyperextension of the big toe.
- Crease on bottom of the foot that was not present at birth signifies that a foot has been made complex. Complex feet should be handled by doctors skilled in such – there are only a handful of them in the world.
  Doctors Who Can Manipulate Complex Feet
- Feet that begin to have a crease on the sole that was not there at birth – your doctor is making the foot complex, which means it will be hard to fix this foot and you will need to find one of the *very* few doctors in the world who are able to fix complex feet.
- Feet can be "overcorrected" and look crooked. Get a second opinion immediately.

BnB

- Sharp reduction of hours from 23 hour wear to 12 hour wear is *not recommended for best success preventing relapse in the first year, and in subsequent years.*
  - If the first 3 months of bracing at 23 hours is critical and we are warned just how critical it is, why is it ok to have a sharp drop in hours?
  - Babies are especially vulnerable to big changes in their life. For months they were used to wearing the brace for 23 hours and a severe shift away can be very shocking. This can lead to rejection of the brace.
  - Many parents are looking forward to bracing less, but this also increases risks. Just because some children were "just fine" dropping in hours and never relapsed doesn't mean it will be the same for your child.
  - In the event of a relapse, being able to say "I did *everything* I could as a parent for my child" will eliminate a lot of potential guilt you may have over how you did things.
- Ending BnB before age 5. *See relapse rates on Page 7.
- Doctors who state that BnB makes any form of correction to the feet – it only maintains the correction.
- Doctors using experimental braces. If you can, insist on proven BnBs, as outlined above.
- Doctors who have little or no concerns over open sores.
- Doctors who insist on 23 hour wear for the first year or until baby is pulling up. 3 months of 23 hour wear is all that is needed, followed by a gradual reduction of hours ending with 12-14 hours at the first birthday. This is then the amount of hours to be braced until 5 years of age, preferably staying closer to 14 hours and bracing during naps and sleep, when muscles are at rest and prone to relapse.

Starting Boots and Bar
Congratulations! Usually, the first week of boots and bar is the most difficult as baby adjusts to the feeling. Power through it, *it's rough.*

What to watch out for in your first week:

- Is the foot slipping out of the boot? Only two reasons exist for why this happens – either the boot is not on tight enough (should be tighter than you think is tight), or the foot is not corrected.
- One more rare reason for slipping out of the boot is that a plantar flexion stop (PFS) piece is still attached to the boot (most clubfeet do not need the PFS). A lot of times an orthotist will order new boots and not notice that they have ordered one with the attachment on – it is a plastic piece that is screwed onto the back of the boot and can easily be removed by taking off the two screws and pulling it off with a bit of force. The PFS is used for older children (not in their first year) who typically will point their feet like a ballerina.

Tips for putting on boots:

- A tight fit is **critical**. More critical is "***no movement inside the boots***". For ladies, we have all worn a new pair of heels – we all know how fast a blister can form. No movement means no friction to cause blisters.
- The tongue goes between the middle strap and top strap, with the small circle on the tongue peeking out between these straps, *not* across the middle where the foot bends.
- After putting on the middle strap, pull the tongue toward the buckles. If you ever see a small vertical line on the skin of the top of the foot after taking the boots off, you forgot to pull the tongue to straighten the material out and it has left a "pinch" between the tongue material and buckle.
- After putting on the middle strap, ***push and pull*** on the boot to check for movement in the little circle. Checking with the "tip of the finger" is not accurate – everyone has a different sized fingertip. The best practice is to watch for movement in that small circle.
- Put on the bottom strap, it should also be tight to hold the foot down.
- Put on the top strap, this can be a little bit looser to allow the ankle to bend a tiny bit and give a more comfortable feel.

In the first months of 23 hour wear, you can take the boots off for half an hour in the morning and half an hour in the evening, though an additional half hour every day is ok if you feel you really need it. After a quick wash down of the feet and between the toes, dry everything (even with a blow-dryer) and you may apply a small layer of Aquaphor "healing ointment". Let it absorb into the skin for 15-20 minutes before you put on the boots, no need to remove the Aquaphor.

What to Expect After a Relapse
A first or second relapse, maybe even a subsequent relapse, should be treated with further stretching of the foot via casting, then bracing with boots and bar. A doctor who jumps to surgery is a huge red flag – a doctor should try any non-surgical route prior to discussing surgery.

Bracing after relapse: Normally after a relapse you will want to go back to longer hours bracing with BnB, at least initially. It doesn't mean 23 hours daily, but definitely longer than 12-14. Then reduce gradually (accelerated of course, due to advanced age of the child) until reaching 12-14 hours, preferably closer to 14 hours. It can be done, there just needs to be a want and drive to do so.

A conservative approach to bracing following a relapse could be the best chance to keeping the foot corrected. A daytime ADM ***in addition*** to BnB bracing could be helpful, only during daytime. Boots and bar should be used for night bracing. Once a child has relapsed, there is an increasing risk that they will relapse again and that surgery will be required. The best way to avoid a relapse is long bracing hours.

ATTT Surgery (anterior tibialis tendon transfer)
A relapse in the later years of the Ponseti method (after 2.5 years +) can signal the need for ATTT surgery. Presently, there is insufficient information to properly counsel families whose infants are beginning Ponseti treatment on the probability of needing later tendon transfer surgery. Typically, a doctor will try re-casting the child after a relapse, or a couple of relapses, before going forward with this surgery – the idea is to do everything possible without surgery before determining that surgery is necessary. The typical age for ATTT surgery is 4 years old. The foot is usually cast for 3 weeks prior to the operation, surgery is conducted, followed up with 6 weeks of post-operation casting.

How can a parent help to avoid the ATTT surgery? Bracing, bracing, and *more bracing.* "Parent-reported adherence with bracing reduced the odds of undergoing surgery by 6.88 times, compared with parent-reported nonadherence."

There are different methods to the ATTT surgery. The commonly used techniques for anterior tibial tendon transfer (ATTT) for clubfoot are split transfers (Hoffer), whole transfers to cuboid (Garceau) or 3rd cuneiform (Ponseti).

Surgery:
~30 minutes pre-operation preparation
Expect to sign off on more procedures than are actually planned to be done. The doctor may need to make adjustments while in surgery if needed, so this is the norm.
Surgery takes roughly 2 hours.
Extreme pain can come when your child wakes up. Be prepared for the worst.

Most Helpful Items:
- tablet, Nintendo (with a brand new game) Disney +. No screen time limits this week.
- ice packs
- inflatable foot rest
- extra pillows
- portable adjustable table
- timer for meds

Questions to ask:
1) How many casts are planned prior to surgery?
2) What is the length of time the physician utilizes non-weight bearing casts after the ATTT?
3) What does the physician utilize for pain control after surgery? (Nerve blocks, oral medication)
4) Is bracing suggested after surgery and casting is completed?
5) How does the day of surgery schedule look? What can we plan for?