**Appendix 2: ITW Parent Survey Open Comments**

*Comments in reference to Section 1:*

* We have found many doctors don't take it seriously. Primary care doctors don't really know which referrals to make (i.e. to which type of physician). The pediatric orthopedic doctor basically told us that if it didn't bother our son, it shouldn't bother us, and he seemed annoyed when we kept wanting a solution after he ruled out causes like cerebral palsy or a shortened Achilles.
* We randomly asked our Pediatrician at our child's physical. It wasn't something they were necessarily looking for, or something we knew could be a serious issue. Knowing that it can be an issue and where to go from there is so helpful.
* My child went 6 years walking on his toes before a PT just mentioned while at another one of my kids therapy's how dangerous/bad it was for a child.
* We were able to diagnosis, we were just in need of help with treatment
* My son did not have an autism diagnosis until after the therapy.
* I wasted time trying physical therapy when my son's toe walking was behavioral.
* My primary Dr. didn't take my concerns seriously enough. Finally found Dr at Children's who said toe walking is a serious threat to a child's development.
* You would expect the pediatricians to be more aware of this but I have seen it is the therapists.

*Question 2.1 Who first expressed a concern about your child’s toe walking?*

*If other, please specify.*

* A child at day care. Professionals ignored it.
* A PT that was treating my other child
* Friend that is a pediatric occupational therapist
* Friend noticed my daughter walking at the pool
* Friend

*2.4  What medical provider(s) were you first referred to for evaluation and/or treatment of your child's toe walking?*

*If other, please specify.*

* Rheumatology
* DDBP
* Pediatric surgeon
* Cardiologist

*Comments in reference to Section 2:*

* We were told casually by certain people, medical and non-medical, that he would grow out of it. Instead, I like to say he "grew into it," meaning the habit just got worse with age. He went from walking on his toes occasionally to doing it all the time. Our first referral was to orthopedics, who referred us to neurology to rule out cerebral palsy or something, and then we were referred to physical therapy. We didn't get a referral to orthotics until we requested it, and that was only from our PCP. The orthopedics doctor didn't want to do it until he was seen again by neurology and orthopedics for another time.
* Help was giving at his school. Three times a week.
* No one referred me. I insisted on further information.
* Nothing else was referred
* I think it was too late for him. He had casts on his feet his toe walking was doing a lot better. But he didn't care about the PT and the pt said he was wasting her time and hes 18 now back up on his toes.
* I think she was 5. I am not completely sure.
* My child had other medical conditions in which she was already in PT/OT for so we kinda worked on all of it at the same time.
* ITW has always been more concerning to us as parents than it has been to our pediatrician. We saw OT for several months to see if it would be helpful to give her more sensory feedback, this lessening the ITW. We did not find this helpful. Our daughter is very strong willed, bright, and active. She is also incredibly tall for her age. So we find that she is constantly trying to grow into her body. So we started PT, with weekly sessions and a basic foot insole. We did exercises at home as well. Switched to a molded foot orthoses, that cupped her heel and stretched the length of her sole.
* Did OT first to see if sensory related.
* My child's doctor did not express concern about the toe walking. I was the one who was concerned and addressed it. The pediatrician did refer me on after I asked the questions.
* I have always been the one pushing for a referral. We have a family history of toe walking into elementary school and I feel like that was ignored. I pushed for an initial referral and was only given stretches but nothing was done to stop the behavior from happening. After 2 more years, a lot of cowgirl boots, my child was still toe walking over 90% of the time and had begun to lose range of motion. Now we are in hinged orthotics.
* We were told by multiple pediatricians that as our daughter got bigger she would eventually outgrow her toe walking. We kept waiting and asking different doctors. Finally we were fed up with waiting and saw that her toe walking was drastically starting to effect her life and her activities. We sought out a doctor on our own at Children's Hospital and someone finally helped us.
* After being told my daughter would outgrow the toe walking by 2 different pediatricians I finally requested an evaluation with an orthopedic surgeon when my child was 8 yrs old.
* I brought it up at age 2 years, 9 months but the pediatrician said to wait and see if she still did it at age 5 before going to PT.
* The PT recommended neurology referral based on her evaluation. Nothing was found and PT was continued
* We were referred to an orthopedic surgeon by our PT. The surgeon did not review our child's information from the PT on the second visit. First visit, he recommended surgery. Second visit, not looking at any of the information from the PT, he stated your child has a perfect arch and should be put in a textbook, even though he did not even watch him walk in order to make this determination. Talk about being confused & frustrated as parents worrying about cutting on your child versus not. The orthopedic surgeon was with Cincinnati children's Hospital. The PT is Dan Cross w/ First Steps. He was simply amazing with my child. We got to a point after our child turned 5 & moved on to a PT with St. Elizabeth MC, who is fabulous as well, she casted (it lasted three days bc my child couldn't tolerate it) and then we were referred to Rehab doc Suggested & administered Botox which was supposed to work to stretch out his muscles, but it failed completely. However, the PT did use a stem machine which my child responded to quite well & Which we continued for a bit and then just stopped going. No fault of hers.
* I don't remember how old he was.
* These questions were had to recall but we noticed his toe walking early on (family and friends questioned us about it) but we were told by doctors at the time that he'd out grow it. Then as he got older we noticed he ran on his toes in baseball (in addition to walking). We became more concerned when we noticed he could not flex his feet while stretching in Taekwando and he was expressing great discomfort when trying to stretch his feet and legs. So we finally again approach our doctor who finally recommended an evaluation.
* I had to push and even change pcp's before someone actually paid attention to my daughter and referred her to Shriners orthopaedic center, who then referred us 4 months later to physical therapists for serial casting.
* She was not referred to PT, she was seen by two different Orthopedics serial casting or surgery was the recommendation from the beginning.
* The first Orthopedic Specialist we saw told me that my son had a tight Achilles tendon and gave him braces to wear at night. At that time, I feel like if my son could have started physical therapy, or if we would have had the information about ITW, we could have avoided the problems that he is experiencing now.

*Comments in reference to section 3:*

* Our PT did her best, but she had not worked with an idiopathic toe-walker before. We didn't know what to expect in the evaluation or what would be a good treatment. She was just sort of reading things between sessions and trying out ideas until we ran out of sessions on our prescription.
* I wish we hadn't been given any timeline, because we were first told in months, and we are now 2.5 years into PT with no clear end in sight. To be told what would be typical would be good, but that every kid is different and can take a lot longer in some cases. Just to be able to establish the mentality for the long haul.
* We did PT for 9 months before surgery.
* When my daughter was 8yrs old the ortho told us there was no guarantee serial casting would fix her, it would just hopefully break her of the habit. So we opted to pursue physical therapy at that time instead since the casting seemed so drastic. I wish we had casted her then because the PT was a waste of time. She was noncompliant at home and we ended up casting at age 11. She is still noncompliant at home with her PT and still walks on her toes. It's been an extremely costly, time consuming and frustrating experience.
* Focusing the recommendations given to a parent based off of optimal outcomes and why is helpful to ensure compliance
* All of this is important! And we believe now, had our pediatrician(s) been checking to see how flexible our son's foot/leg range of motion/flexibility was at every checkup and had they taken our concerns seriously EARLY ON then his toe walking could have been addressed sooner with exercise or just therapy and the intense treatments he ended up needing to do (series casting, braces and therapy) could have been avoided. And he would have hopefully have had better range of motion/flexibility than he currently does (though now it is much better than it was).
* My son has a more extreme case of ITW so the initial treatment plan that was set up at our evaluation, was exceeded.

*Comments in reference to section 4:*

* We only got educated on ITW when we contacted Dr. Barkocy via the Internet. Our local PT was not educated in the condition and was more or less guessing on the best course of action.
* I wish we would have gotten our child referred to a PT at an earlier age.
* First we had double leg casting...had to remove in three day to tight. Never and will never recommend casting again.
* After the evaluation the therapist scheduled us for maybe 8 more weekly sessions, but it wasn't until the end of those that she indicated that she wasn't seeing enough progress and we needed to be referred to orthopedics for possible bracing, casting, or surgery. I understand now that the process is to first try PT, but at the time I felt blind-sided to suddenly (from my perspective) have these much more invasive treatments being recommended.
* I believe we would have had even better results had my child been diagnosed earlier. While we were presented with different treatment options, there wasn't a preferred option or really any success rates from other cases to be shared - it was still fairly new 4 years ago.
* We are aware that getting children to stop ITW is a challenge and intervening the earlier the better. However, I don't think that we or most families look to treat this very aggressively at dx, at age 2.
* There wasn't so much a "discussion" as a very blunt assessment and recommendation. I was pretty much told: this is what it is, this is how often we are going to do therapy. It didn't feel like i was able to express input without putting the therapist on the defensive.
* We had three different therapists during are few months of therapy. Our child did show some improvement. Every therapist had a different idea or thought process on to why our child was a toe walker. No one had a plan to fix it. They just kept saying we could try this and see if this works. No real explanations.
* We were referred when our daughter was 2 years old. Her older sister has been diagnosed with sensory processing disorder. When the physical therapist became aware of this, she recommended some stretches, to not worry too much about it, and to return in 6 months if it persisted. The toe walking persists, yet we have not returned to PT (almost two years later).
* my answers above are only for the second PT evaluation. If I were to answer based on my initial concerns, my answers would have been no to everything.
* I wish we would have not been told repeatedly that she would outgrow ITW. Treatment at a younger age might have been easier. Although being a bit older she was able to understand better.
* We were referred to another Rehab doc, Dr.Vargus At Cincinnati children's. She was absolutely fabulous with my child. She was able to hold him accountable for his actions with keeping up with PT. She explained and was open as to outcomes and that we were always welcome to come back even just to check on status for our child. Our child was casted by Amy Taylor-Haas for six weeks at of 10 years old(4th grade) Dr. Vargus, Amy, & his pediatrician, Dr. Bill de Buys, were always in contact with each other & in the loop regarding treatment and outcomes.
* All treatments, frequencies and durations that were discussed at the evaluation were in a matter of: Let's start with this, see where that goes, then be aware treatments could involve this or that and possibly take many months. (Our son's older age for diagnosis was against him)
* Pt was done not to treat the toe walking but instead as an effort to maintain and reclaim so range of motion

*Comments in reference to section 5:*

* Not sure how to rate "important," so my answers were more about what was relevant to my son. The "wait and see" approach was what was tried first. Next was stretching and gait training. Then we found out about orthotics. He has not been back to a PT since he got his braces, but we are trying to get that referral.
* Unsure on 9-11, never received those services.
* Physical therapy worked for our child. Through our school. Casting failed.
* It would have been great to have had information from the outset about the different treatments for ITW and the order in which they are tried and why (some seem to be to improve gait, others to improve range). For example, no professional explained to me that AFOS wouldn't work because my child's range of motion was too limited. They just said they weren't an option. Another parent explained it to me. Also, someone needs to warn parents about treatments for which there is no empirical support, like vision therapy. I also had a professional (PT) recommend my son have surgery on his tongue tie and see her for special "postural and respiration" therapy. She felt if he would breath properly he would stop toe walking.
* For us, the only option that showed significant results was serial casting. All other treatments were nice to have - not essential. Had I known the limited progress after the initial treatments, we would have gone straight to casting.
* I don't know that they are "not important". We just didn't experience them.
* I happen to work at our pediatrician's office and I did ask the providers about full leg/up to the knee orthoses. We don't see any children with these for ITW. Luckily our daughter can physically still walk with a regular gait, or her calves are not tight etc.
* We have tried pt, braces, stretching and nothing has worked. My son is almost 10 and has toe walked since he started walking as a baby. We have been hoping he would out grow and he hasn't. In fact it's getting worse. We are going back to children's hospital soon to see about Botox. My youngest son who is two started toe walking as soon as he was walking as well. He was put in in braces at around 16 months and used them for 6-9 months. They worked very well. When has shoes on now he will walk normal, but barefoot will go up on his toes. He will listen to cues to walk flat feet. We are kind of at our wits end with the whole thing. Know one seems to have any answers for all this.
* I was mostly interested in the less extreme intervention choices and learning what I could do at home to reduce the problem. I felt pushed towards a brace or casting scenario but insisted we start with therapy and stretching. His ROM increased dramatically and while the problem isn't gone, we now have the knowledge to reinforce stretching and other excercises when we notice him start to ITW and are able to mostly control it without any drastic interventions. This was very preferable to us, as he was almost 5 years old before we were eventually recommended therapy and at that age didn't want to subject him to bracing or casting unless absolutely necessary.
* A regimented approach would have been nice and also to know whay goals we were looking for. Information on why we were doing what we were doing. At first everyone just wanted to put him in braces that cost a lot of money but no idea if they would work.
* If my child does not conquer this, I'm not overly concerned about the future. My husband was also a toe walker, and now manages to hide it when he needs to. My child will do the same as he gets older.
* If these are all treatment options, we feel it is very important that they are discussed as possibilities.
* Some of these like Botox did not apply to my child and was not offered.
* Vision therapy & botox? Did you just throw those in to see if I'm actually reading this?
* This is a strange question. This whole survey is not really phrased toward a layperson parent. "How important are these topics???" What does that mean? I answered based on whether I thought they were helpful.
* I was a little unclear of this question. I answered as to what was important for treatment options for my child. I am sure other children have used some of the other treatment options that I put no on
* As stated in my prior comments, these factors of PT, Exercise for strengthening, stretching, casting, bracing, STEM/electric stimulation options, home exercise plans, are all important from education from the PTS to the parents. Outcomes rest solely on parent participation In order for positive feedback and outcomes to occur. It is a team effort. My child did have bracing for quite a while from Dan Cross, initially, & then after casting, more bracing with "Dr.George" w/National Prosthetics & Orthotics. He was absolutely fabulous with my child and he also held him accountable for his responsibilities with wearing the braces and doing the exercises. Surgery options are especially important that needs to be explained & what the outcomes would be with parents. Especially for ones with a three-year-old, which makes parents nervous & stressed when surgery is suggested when it is not life-threatening. Not to mention the financial burden it would bring upon the family. Vision therapy never entered the equation with our child. Botox therapies, however impressive this option was, it was very expensive ($2,000 a pop) to administer when the outcomes were not known. Home exercises are a great plan Of action to keep parents accountable for progress for their child's overall outcome. The PTS should not bear the soul burden. It is not magic on their part. It is a total group effort for all involved.
* I'm not sure where sensory, visual and Botox play a part in toe walking. Surgery I know is an option (one we had to consider but opted not to do). Our son had to do all the rest! And he struggled and still does, it's hard to get kids to do their exercises without hovering over them constantly. That's a poor excuse but true the older they are.

*Comments in reference to section 6:*

* These answers are regarding our local PT. Dr. Barkocy provided good intervention options over the phone after I contacted her.
* Retrospectively, I think she was an excellent therapist and did what she could with my son. But by not explaining the process to me from the beginning (PT, then more invasive treatments as necessary) she did us disservice. I thought perhaps my son just needed more time in PT. There is also a weird dynamic between the PTs and orthopedists at our hospital. I think part of what was going was that the PT wasn't "allowed" to explain the other therapies because the orthopedist had to order them, and she couldn't "overstep" in telling me things about treatment and prognosis. Unfortunately, the orthopedists are always overbooked and terrible at explaining things so when it is left up to them it doesn't really happen. It would really be much better if there could be a stronger collaboration between the PTs and orthopedists.
* With treatment options being so new, we focused on what was least invasive. Hopefully treatment results are more compelling for newer patients.
* We are happy that this research is being done, as it feels like there are no absolutes. For example if you do PT and orthoses, ITW will be corrected.
* I felt very pushed towards bracing or casting, so doubted whether our therapist would work as diligently with our son - I was concerned that she had written off therapy as something that wouldn't work so wouldn't try very hard to get results, and then be a self-fulfilling prophecy and us end in bracing/casting anyway.
* We had two separate PT. The first I felt like he did not listen to me with concerns. He also did not allow me to sit in the therapies, which I found odd. I would be a "distraction." He would give me a paper of new exercises to add at home. I did not understand why he couldn’t tell me directly. I called ad asked to switch after a few months, I loved our second PT.
* again, these are only for the second PT evaluation and not the first. My answers for the first would have been "not confident." My only concern now is that even though she has what is classified as ITW, no one seems to be able to answer my questions about the mention of possible EDS in my family and the relationship between that and ITW
* Our PT is very knowledgable and but my daughter only goes once a week. Getting her to do the stretches and exercises at home is like pulling teeth. I don't know about other people but my child needs organized activity, led by an instructor. She is not motivated to do this on her own. I wish Pilates and core strengthening was included under insurance for additional therapy for these kids. They have NO core strength.
* I am a physical therapist so I feel I was given the ability to give input in this process which I appreciated and valued
* The serial cast doctor was fantastic and the physical therapy doctor and intern were extremely good! My son responded to them very well, worked hard for them and we would have continued the needed therapy longer with them (for that reason) rather than switching to home therapy only, IF BOTH the therapists had not left the Hospital and went to another state. It was disheartening to loose both the great therapists our son had for treatment after the casting.
* We had to drive almost 2 hours to see a pt whose bedside manner left a lot to be desired. No effort was made to refer us to any of the (many) local PTs.

*Comments in reference to section 7:*

* We have never been discharged. It's ongoing!
* I feel all of these were important. Unfortunately, we went through Children's Hospital in Cincinnati for all of her treatments. At age 9, we were supposed to do follow-ups every six months. Suddenly, Children's was charging a hospital visit price for her PT and we could no longer afford to take her.
* PT is very expensive, as we have a high deductible plan. We would certainly pay it if we saw a great reduction in the toe walking with our interventions. Next step we are going to try is to have new orthoses made by a company that will have carbon fiber foot beds.
* I wish we would've had more follow-up from our therapy. Once she determined he wouldn't need bracing or casting, we were discharged without any follow-up evaluations.
* PT is key. But realistic expectations need to be set.
* All are important and I wish the hospital was better about pursuing parents for follow-up check-ups several times after therapy ends, to be sure at home therapy is continuing and doing what it is supposed to, so as to not undo what has been done. Life gets busy and a reminder to check-in is always helpful!

*9.3  What other medical providers have been involved in evaluation and treatment of your child's toe walking?*

*If other, please specify.*

* Pediatrician
* Leg braces
* Occupational therapist
* Pediatrician
* Primary care physician
* Serial casting
* Psychologist
* Family care physician

*Comments in reference to section 9:*

* He completed physical therapy before he got his orthotics, and it was not really effective. We plan on getting him another round of physical therapy in conjunction with his braces as soon as we can.
* Completed initial treatment plan. Toe walking is improved but gait is still not great. Will be seeking follow up for additional PT/OT in the future.
* My son eventually had surgery for toe walking and that is what corrected it. But we returned to physical therapy following surgery and they have been enormously helpful in maintaining the correction.
* He is almost 10 and still toe walks when not wearing shoes at least 25% of the time!! ROM is WFL but still tighter than normal. Just last year a mild scoliosis was identified and we were referred back to PT for hip/hamstring/ankle tightness. We went twice, primarily for a home program to continue on our own.
* We still battle with toe walking. I would say 15-20% out of 100% he forgets and walks on his toes but corrects once I say something.
* The PT was very effective, but she tends to relapse. I think it would benefit her as well as our family dynamic to be able to have the follow-ups every six months to a year. Unfortunately, Cincinnati Children's is now charging too much for us to to this.
* Re question 9.5 we chose to discontinue PT treatment due to life circumstances and lack of results
* It has not been effective in that she is still toe walking. We do feel like this is not a black and white issue and that we were compliant with the PT treatment plan. We are still glad that we gave it our best effort. And again will be trying the carbon fiber orthoses. Our daughter is 6 now. Our PT is very knowledgeable and helpful.
* My child's toe walking is more sensory related than psychical. The PT determined there was nothing psychical cause the toe walking. It was at that time not causing any damage either.
* It was effective but we changed therapist 3 times and each one wanted to change things because there thought process were different.
* It was effective in the sense that I learned how to help the situation at home. He still toe walks. I see no effort on his part to change. But I learned several techniques from the therapist that will help me to manage him.
* She still walks on her toes when barefoot. With shoes, she walks with a normal gait.
* My daughter started at a -25. PT got her to -12. Surgery got her to positive position where she is supposed to be. I wish we would have started PT at a younger age to avoid surgery. But ultimately happy with steps we took and outcome.
* One session a week is not enough.
* My son is 9 and on occasion, I still find him on his tippy toes at times. He does not do it on a regular basis.
* He kind out grew it... I don't think PT had a huge impact... maybe a little
* My child had periods where she would show signs of increased tightness and increased toe walking after discharge and I felt prepared for this, knew who to contact and how to get help
* After speaking with my child (who is now 12 1/2 years old) & husband about their experiences. My husband said that the PT had no effect on changing our child's ITW. My child said, that he has to think about not toe walking. He said he was being lazy when he toe walks or he is more comfortable walking on his toes. He prefers being on his toes than heels. He said there wasn't a real reason why he keeps doing it. Muscle memory in my thinking as to why. My observations of my child toe walking range from the first thing in the morning he is on his toes we have to tell him to do "heels down & feet together" or he will stub his toes on the baseboards/furniture. He splays when he walks but not as bad after he had PT. He is valgus at his heels & would make a great hockey player. So, we constantly remind him that he needs to walk with the correct gait/heel-toe for better posture or other excuse. The PT, Amy, when asked, if my child's hips or knees were jacked up, looking at issues for when he is older as an adult (back, hip, knee treatments/chirp) she advised me that my kid's tibias were twisted. She was also very thorough with explaining about stretching for when he went through his growth spurt, which hasn't happened yet to this day, but he's getting there, he might have pain from the muscles being rigid/tight & an unable to stretch with his bones. He has yet to experience this factor, but I am just waiting to say I told you so because she hammered that information in his head about doing his exercises. I believe that PT did help him overall & without it, I believe the outcomes to this day would be worse. He plays team sports (basketball & baseball) and is still on his toes from time to time. He is on his toes even during the day but more so at night when he's tired. I believe, overall, that the PT, casting & bracing treatments, along with my TEAM of providers, have made a tremendous difference in my child's life.
* Still does somewhat but remind her not to do and she stops
* The treatments were very effective overall. But we would have continued the physical therapy a few months longer if we hadn't lost BOTH the therapist and the intern that my son liked. The home therapy has not been as successful as I would have liked since PT stopped but that I guess is on my son and us as parents. But it's been hard for him. I wish we had been recommended to start therapy several years sooner than we were!
* My child went to PT for 7 years before serial casting was recommended. We attended a serial casting program at Lurie Children’s in Chicago that finally resolved his toe walking. Those PT's do understand Toe Walking and how to resolve it. It was a 2 year long process.
* Pt at home still on going. No other pt recommended. There was a mention of a referral to a ped neurologist, but never made... She still goes up on toes sometimes even after 6 weeks serial casting, braces and home pt.

*10.1 How did your child feel about their walking, pain, and/or function prior to physical therapy?*

* He didn't like that he walked differently or couldn't stop toe-walking. He also got tired of hearing reminders about walking on his feet. He didn't feel pain in toe-walking, but other movements that should have been easy were painful or impossible.
* Complaints of mild pain
* She was completely unaware.
* I'm not sure how to answer since he's had PT before and after surgery for toe walking. Before surgery there was no change in toe walking at the end of PT.
* no comment
* Didn't really have pain and it was his 'normal' condition. Didn't really think anything about it
* States it hurts to walk up stairs and long distances. No other concerns
* Didn't care.
* He didn't really notice or complain about it.
* Did not understand what was happening and why
* Little embarrassed
* He had no awareness therefore no concerns!
* Never said a word about it!
* She's too young to really notice. She only realizes she's on her toes when we ask her to walk on her heals and then she corrects but quickly forgets.
* He was very high on his tip toes
* She knew it made her different, but didn't worry about it too much. When she had her braces, she liked it for a bit then wanted them off. There are times when I am reminding her to walk on her heals that she asked for the braces again.
* Good
* she was to little
* No pain
* Had recurrent pain before PT
* Unknown
* No issues
* She did not have pain nor express any feelings one way or the other about her walking.
* He was unaware of his toe-walking and did not complain of pain at age 3.
* She thought it was a normal part of life and it mostly went unnoticed unless she was aggravated by parents telling her to put her feet down.
* No concern
* Our child didn't care because she had no pain and also didn't see that her toe walking was different from other kids. Again, physically at least for now she can walk with a heel toe pattern. Her preference is to toe walk though.
* Not aware
* He didn't seem to notice
* He didn't have any pain, but felt different from other kids and wasn't able to run as well.
* Not good
* Too young to understand
* My child didn't seem to have any pain or discomfort from the ITW. He did trip more often than his counterparts when he got ahead of himself but it never caused any injury.
* He never seemed to care that he walked on his toes. It has never bothered him.
* They did not know any different.
* Did not bother him due to his age,
* Good
* He was unaffected. His doctor noticed ITW at a routine checkup and referred him to a PT.
* No pain. He says it's just more comfortable to walk on his toes.
* shes so severe she doesnt notice or complain
* She was too young to have thoughts on it. She did not experience pain. She walked on her toes more than 50% of the time prior to therapy.
* No pain or limitations to her functionality.
* She did not have any problems with walking on her toes, did not bother her.
* She didn't seem bothered by it. She still continues to walk on her toes now.
* It was most comfortable to her to walk on her toes because she had always done it.
* Our OT made all of the therapy/exercises very fun and enjoyable!
* She didn't notice it.
* No pain before physical therapy
* She felt that she walked fine.
* She told me her legs hurt when she jumped. She was clumsy and frequently fell for no reason
* He never noticed or complained.
* Unaware, normal function
* Irritated. She got teased. She got tired of people telling her to walk flat. She hated her lack of shoe options.
* She didn't think there was anything wrong.
* Poor balance
* Didn't notice it
* Thought it was normal to toe walk
* Didn't really mind being on her toes
* She didn't think she had an issue
* I'm not sure that my son realized he had a problem. His tippy toeing wasn't as severe as others.
* Don't know
* embarrassed as she didn't walk "like her other friends"
* It never bothered him. However, now that he is older and playing sports it does effect him more. Creates pain in joints
* She felt embarrassed for walking on her toes.
* She was too young to know any different
* He didn't even notice he was doing it.
* She sort of enjoys her toe walking. She is not embarrassed by it or in pain. At school the students all think it's cute and she still does it now in 5th grade. She can walk flat after physical therapy. She just chooses to still toe walk.
* Complained of a lot of pain in feet.
* He was 2 or 3 years old. No pain ever mentioned.
* She had no idea she was doing it.
* N/A
* He was very frustrated that he couldn't keep up with other kids. He also didn't like that his heel and calf would hurt if he tried to walk normal.
* totally fine, he never noticed anything
* No problems
* He did not seem to think it was that big of a deal until he needed to start flexing his feet for Taekwando and he couldn't without great pain and discomfort!
* Did not realize she was toe walking
* unknown, child was not yet talking
* Resisted my efforts at home to correct or treat her toe walking. She did it without even thinking.
* He complained that his feet hurt when walking around the store or being on his feet for awhile.
* It never bothered him. His toe nails are a mess b/c he's always on them and his shoes wear out quickly. He has trouble wearing sandals or slides b/c he can't walk on his toes and keep them on at the same time.
* Never noticed it
* Right up on his tip toes, constantly falling over, and so tight in muscles that he was never on his flat feet.
* He didn't notice it
* He hurt all the time.
* Child had no clue that he walked differently than anyone else. Mild pain. Could do anything any other 3 yr old could do
* She didn't seemed phased by her walking but didn't enjoy the pain when we'd ask her to stand flat foot
* Unknown
* The child had no concerns.
* He was barely 2 and was unable to physically flatten his feet without discomfort.
* A lot of pain and inability to participate in many physical activities.
* She was too young to say.
* Frustrated, painful, resistant
* Struggled a lot
* She does not think it is a problem and dies not eant to correct it.
* She doesn't feel pain in walking on toes and she is able to walk normal. But after few seconds ahe again start walking on her toes.
* Not much bother
* He wanted to walk normally because kids at school teased him. He didn't have any physical pain.
* Frustrated
* Not great

*10.2 How did your child feel about their walking, pain, and/or function at the completion of physical therapy?*

* He felt more stretched out. It was physically easier to walk on his feet. But it did not break the habit.
* No complaints of pain
* N/a
* I'm not sure how to answer since he's had PT before and after surgery for toe walking. efore surgery there was no change in toe walking at the end of PT.
* no comment
* He saw a big improvement!
* N/a
* Haven't completed pt
* He was very proud and was able to keep his balance, jump, stand on one foot, put heels to the ground, etc.
* Was happy
* Better, more confident
* Better awareness but honestly, he could really care less...but was happy to be out of the braces.
* He noticed pain from exhaustion because of moving muscles he never used.
* Have not completed PT yet.
* He was alot better
* She was proud of herself, but knew it would be an ongoing issue.
* NA
* Her answer, it makes me who i am.
* No pain
* Decrease in pain
* Positice
* Not yet completed
* She is now aware of her toe walking and does express some pain occasionally.
* Unsure
* She has gained a lot of confidence in her physical "normality" now and the way that she walks. She still complains of leg pain when walking far distances, though.
* No difference
* No change. It's really our concern as parents that eventually she will physically not be able to walk heel toe. And hat this can lead to injuries and other problems.
* Better when she could walk without going up on her toes
* He experienced some discomfort at first. I believe he was made more aware of it and aware that he could self correct
* He felt the same as before. The little bit of PT he did get didn't seem to help much. When I tried to get him back into it, there was never an opening at the location we needed.
* Not good
* To young to understand
* My child's ITW was virtually nonexistent when he was done with therapy. However his ITW has returned over time and we are now scheduled to have him reassessed. He has not had pain throughout his experience with ITW.
* He enjoyed the stretching activities, and do it felt better to him to have completed.
* It holds him back. He can’t physically do things like other kids.
* He was more confident, but he was older and realized kids were starting to take notice.
* Good
* He seemed happy that he was "walking correctly," but wasn't much effected by it as he wasn't aware he was doing it before and it wasn't causing him any pain.
* Same
* no change
* She was too young to have thoughts on it. She did not experience pain. After therapy her toe walking decreased and her ankle mobility increased significantly.
* Same. Understood difference between toe walking and flat feet.
* She was happy that the adults, ie parents and therapist were pleased with results
* The same as before she started therapy
* She feels good about walking properly now.
* By then, he adored our OT and was happy to do anything she instructed.
* The same
* No difference
* She still wears braces at night.
* we are not yet finished with PT but she is doing well
* N/A
* Did not complete therapy
* Good about herself, but still frustrated that we had to have surgery.
* We're not finished with PT yet but she's still in denial that she even has s problem
* Balance is better but still toe walking
* N/a
* No difference
* Still seems to be a problem
* She doesn't realize she was toe walking
* I think he was happy to have the PT behind him.
* N/a
* much improved and more confident
* He was very young so he was happy about not going to appointments anymore
* She still felt embarrassed but not as much.
* She was confident and happy that she was walking typical. But still pretty young to really notice
* We aren't done yet
* She found the stretching and exercises somewhat painful. She did not find joy in treatments or at completion. She was ambivalent.
* Minor pain with extended use (long walks, running etc.)
* He said, "I didn't care." He was glad it was over so his life wasn't interrupted. Now in all fairness, I do remember him being happy upon completion & the overall success of PT treatments that each "milestone" victories that occurred.
* She was confident. She was also happy to know she would no longer have to wear her braces.
* So happy to be walking and more independent. So proud of himself.
* He feels more confident about walking and doing other activities.
* still fine but somewhat more aware :)
* No problems
* He felt much better than where he was before he started all his treatments but he was disheartened when he first lost his therapist, then lost his intern therapist (both moved on to different positions out of state). They were motivating for him and he needed that for awhile longer.
* Same as before
* unknown, child was not yet talking
* Her legs feel stronger and she rarely, if ever, walks on her toes. If she does, she corrects herself.
* Still some complaining about discomfort, but a decrease.
* It still doesn't bother him. At this point we are not pursuing any further action. He has the range of motion now but his brain just won't reprogram. It hasn't stopped him form anything so further action is not worth the time or money. The serial casting was the most successful as it gave him a much greater range of motion. He could barely get his socks on prior to that. He wore both casts and it never slowed him down. The braces were always a battle. He always complained they "hurt" or bothered him in some way, even while sleeping. We tried sleep ones and regular ones but our insurance refused to cover ANY of them so that was a huge waste of money. It is also almost impossible to get them to fit into regular shoes. By the time you pay for them they out grown them.
* No comment from him
* Stretched and muscles more relaxed
* He thinks he walks better
* He did not like having to go to therapy weekly for 9 years. He’s glad he doesn't have to go anymore.
* Aware he walks differently. Increased pain. Gets leg/feet fatigue easily. I don't believe this is for to PT treatment, but instead due to several growth spurts, continued toe walking and maturing a bit and becoming more self-aware
* Proud
* Unknown
* I still have some concerns as the issue is not fully resolved.
* Makes progress but growth spurts set him back
* Less pain, still unable to do much physical activity, but should improvement. She constantly complains of right Achilles tendons.
* She was too young to say.
* Same, maybe achieved a little more stability temporarily
* Similar
* N/a
* Don't know
* Exhausted
* He has not completed his therapy but he is more capable, physically, of participating in the sports that he likes to play, like Football and Volleyball. He feels like he can run and keep up with the other kids, where before, he could not.
* That he doesn't know he's doing it. It isn't helpful
* The same
* N/A

*10.3 What did your child like about physical therapy?*

* He liked his physical therapist. He liked his actual sessions pretty well.
* Fun activities. Interaction with therapist
* She likes the games she gets to play, and gym space at the clinic, and she loves her therapist. We had a therapy dog there for a couple appointments and that seemed to be very helpful for her.
* Games. The positive and friendly attitude of the therapist.
* no comment
* He enjoyed the therapy process and the 'play' time.
* N/a
* Liked therapists and activities
* We loved our PT's! They were very interactive with him and played games. They made it fun, but also made it count.
* The therapist
* The variety of exercises.
* Obstacle courses and games!
* He liked playing with our PT.
* New toys
* Not much he was a complaining teenager
* She had fun with her therapist. She knew that she was working on her walking but really felt it was a playdate with all attention on her and she enjoyed it.
* NA
* getting to use the fun toys
* Fun activities
* Interactive
* Provider
* one on one friendly attention; allowing my child to make some decisions for himself
* She really enjoyed the attention and games.
* Friendly female therapists that he bonded with.
* She loved the activities and that it wasn't traditional exercises. She was stretching and strengthening while playing games or completing tasks, so she more willingly participated.
* Games
* She loved the attention and the activity because she is a very active child.
* The play aspect- treatment made into fun games
* The games/interaction
* It was fun.
* Nothing
* Playing stretching games
* Simply put, our therapist was amazing. She was fantastic at her job. She was very good at communicating with my son and making the experience of therapy fun and productive. My son enjoyed the activities that involved toys he liked to play with and responded well to all of the instruction. I would say the entire experience was positive for him.
* He did not like attending therapy, but he did like doing the stretching and exercises at home.
* Learning new things
* The assessments of strength, balance, etc.
* Good
* His PT was so sweet and kind and always had fun games and toys for him to "play with" during their sessions.
* He loved the equipment, and he really liked the therapist.
* her therapist was great
* She thought is fun. Her therapist was excellent in making therapy like play time.
* Games.
* The games incorporated into therapy
* Playing with the toys
* the games and toys
* The games, toys and physical challenges.
* She was two years old - she played on the playground.
* playing in the trampoline
* The physical therapist.
* The therapy is fun and engaging. She looks forward to going each week
* He loved "playing" with his therapist. He loves doing the duck walk.
* Fun activities
* Therapist played a lot of games, came up with fun activities and always listened.
* She doesn't like PT at all.
* The games
* Attention
* The fun he has with the therapist
* Fun, nice therapists
* Treadmill
* My child liked how the PT incorporated games into his therapy sessions.
* Playing
* increase in ROM and balance, loved her therapist Colleen
* Not much. But he did feel more flexible afterward
* She liked it, she really liked the therapist.
* She enjoyed the activities and thought of it more like a gym than a medical facility.
* The fun games the therapist did with him.
* She enjoyed getting out of school frequently. She enjoyed the therapist. She liked having her legs massaged.
* There was not a lot she "liked" about it, but she knew she had to push through.
* He said "Dr. Amy". He was bribed early on & he loved getting rewarded, but as he got older he just wanted the toys but didn't want to do the work. He also said being on the iPad when she was doing TENS/electric stim.
* One in one time. And the games they played during therapy.
* The therapist...the fun they had playing together.
* He liked his therapist and the treadmill.
* the 'games'
* really liked her therapist
* The doctor who did the serial casting was very kind and relational. He let my son watch movies during the casting procedures and let him pick the color of his protective wraps each week. The physical therapist she was very kind and took the time to explain things to my son so he'd understand. The physical therapist intern went above and beyond getting my son motivated to do his therapy and exercises. Actually he was the only one who could! My son really liked him and cried when he learned he was leaving.
* Sensory play
* unknown, child was not yet talking
* They made the therapy into games and activities so she rarely noticed the stretching or discomfort.
* Play
* He loved PT and his therapist. No problems there but he just went right back on his toes once we were done.
* Walking on balance beam
* How they treated him and made him feel comfortable
* Functional exercises
* His therapists became his friends.
* All the activity and games
* The physical therapist was kind and funny. She loved getting her serial cast changed and picking new colors each time.
* Liked playing games
* The therapist had some fun toys!
* The activities
* Nothing
* Too young
* Interacting with the fun therapist games and activities sometimes
* Fun
* Na
* Don’t know.
* Not every time
* He liked the physical therapist. That is all he really like about it.
* Fun and interactive
* He liked that they made it fun
* N/A

*10.4 What did your child dislike about physical therapy?*

* He did not like walking on a treadmill (extreme uphill). He didn't like being asked to do stretches at home.
* Casts
* Having to slow down and follow specific directions.
* The hard work. The home exercises.
* no comment
* The frequency of the visits and how it interrupted his other activities.
* N/a
* Some things were hard
* Wearing braces and stretching.
* Stretches
* Some exercises were challenging
* ANY stretching. Boring! (For him.) We continue to struggle with incorporating this into our regular routine due to his resistance and preference to do almost anything else.
* He said "there was nothing to dislike."
* Inconsistencies on who was providing the therapy that day.
* That he had to do it.
* The only time she disliked it was when it was scheduled at a time when she would have preferred to do another activity such as a playdate with friends.
* NA
* nothing
* Nothing
* Kinesthetic taping
* Having to work.
* Nothing
* Nothing, she really enjoyed the whole experience. She did not, however, like the orthotics used.
* Doing home exercises between therapy visits.
* Her legs would hurt sometimes from all of the activity.
* Stretching
* Sometimes we had trouble getting her to do daily exercises at home. We had to do a lot of things to make it fun for her.
* Serial casting and stretching exercises
* He would get impatient with the repetition.
* Nothing. He liked it all.
* Na
* Wearing orthotic braces
* I don't think there was any part of the therapy that my son didn't like. Even when he was asked to do complex tasks he still seemed to enjoy himself which I think is a testament to my son's therapist.
* He felt bored at therapy. We were in a busy OT/PT room and he saw lots of other children doing things that looked more fun than his stretching. He always wanted to do this other activities but was never able to. And he would often be distracted or upset.
* Nothing.
* The braces and chipmunks. Also the pain of stretching
* Nothing
* N/A
* Nothing
* all the work she had to do
* She was content in therapy. It was an hour long and her attention and focus was sometimes a struggle.
* Being told what to do (she was two and the structure was hard it she didn't want to participate).
* Being stretched/manipulated by therapist
* Nothing
* when she had to do something for a long period of time
* Nothing
* Physical manipulation of her legs by the physical therapist
* n/a
* Wearing the braces at night.
* At times the braces can be uncomfortable and she worries that she looks different from other kids.
* He has a hard time focusing and doing one thing at a time.
* N/a
* Some of the stretches were painful.
* "It hurts", she has to wake up early to make appointments before school so she doesn't miss class. She refuses to wear her leg braces because they are embarrassing.
* The stretching
* N/a
* Stretching his hamstrings
* She liked it.
* Some exercises are hard
* He wasn't always excited about doing the exercises.
* Some exercises that were hard
* the time spent in the PT office
* just having to go weekly
* All the therapy :)
* She was pretty compliant with all interventions and didn't really ever display not liking anything that I remember
* Stretching and walking flat footed.
* She felt it was repetitive and didn't like the stretching. She didn't like the night time braces.
* She disliked having to do it, but I think that has more to do with her age and attitude.
* Doing it. He hated it because he was forced to do something he didn't want to do. He did say it was painful, however, in my mind that means it actually was working, which was a good thing.
* The stretches.
* Doing something not of his choosing.
* He did not like doing the at home exercises.
* the pain
* Heel walking
* The pain of setting his feet each week. He hated not being able to fully participate in recess and gym while in the casts. He hated sleeping in the braces (they were too warm), embarrassing to wear the braces (not as "cool" as the casts) and it was a struggle to motivate him to do his at home therapy especially after losing his therapists!
* Medical environment - she has a fear of the doctor so would get upset in the waiting room
* unknown, child was not yet talking
* Some discomfort and her legs hurt with focused stretching exercises.
* Home stretches
* nothing
* probably the orthotics
* Castings but he needed them for a long period of time
* Stretches
* He didn't like have to go!
* Doing the games more than once and doing the same thing each visit. It did get boring for him
* The pain at night that came with the new stretching and wearing AFOs in the heat
* Disliked the repetitiveness
* She was somewhat impatient with the evaluation and exercises. She just wanted to play.
* Sometimes stretching
* Everything.
* Too young
* The discomfort or tiring activities
* It hurt
* Na
* She is 2.2 year old and I don't know about it.
* Stretching
* It was really hard for him to do the stretches because he was so tight.
* No dislike
* That it hurt
* N/A