On October 7-8, 2005, Allyson, Joshua (6 ½ years old) and I had the opportunity to attend the Ponseti Method training symposium at the University of Iowa. It was fun to see everyone there. I will try to provide some detail on the meetings and presentations but please understand that I am a parent and not a doctor and am giving my impressions of what was presented and it may not be exactly what the doctors meant to say. Hopefully it will be close. If anyone sees anything that is not accurate, please let me know and I will try to correct it.

There were about 30 doctors there from 10 different countries. Those that I knew included Dr. Dobbs from the St. Loius Shriners, Dr. Penny from Victoria B.C., Canada, Dr. Naomi Davis from the U.K., Dr. Mark Sinclair from Germany, Steve Mannion from the Malawi Clubfoot project, a doctor friend of Sanna Rekalia from Finland, a doctor from Turkey who was studying with Dr. Noonan at U of Wisconsin, Michiel and Marieke Steenbeek, of the Uganda Clubfoot project. Also, Dr. Ponseti, Dr. Dietz and Dr. Morcuende from Iowa. A day earlier, they were discussing the efforts to take the Ponseti method to developing nations. There are now Ponseti clubfoot projects in Uganda, Malawi, Ghana, Nepal, China and India. The U of Iowa is also involved with training projects in many Central and South American countries.

It was great to have Boston and NY Marathon winner Alberto Salazar there as the honorary chairman of the Ponseti clubfoot races held on Saturday after the meetings. A brief biography of Alberto Salazar can be found at http://www.distancerunning.com/inductees/2000/salazar.html

My guess is that there were probably 20 Ponseti method patients, and their families, there ranging from infants on up to two gentlemen who were 49 years of age.

The following is the outline of the 2 day meetings:

FRIDAY, OCTOBER 7, 2005

8:00am Registration. Continental breakfast available.

8:30 Welcome - Jose Morcuende, MD

8:50 Stan James previews the Ponseti Clubfoot Races

9:00 Dr. Buckwalter provides bio on Alberto Salazar and names him Honorary Chair of the Second Annual Ponseti Clubfoot Races to be held Saturday Afternoon.

8:45 "Kinematics of the Subtalar Joint:

Why the Ponseti Method Works"

--Norgrove Penny, MD

9:30 "Pathology of Congenital Colubfoot:

Errors in the Treatment

--Ignacio Ponseti, MD

10:00 Break

10:15 Casting babies. Tenotomy, if possible.

12:15pm Lunch

1:15 "Technique Practice with Models and Instructors"

Instructors:

Frederick Dietz, MD, Jose Morcuende, MD, PhD, Norgrove Penny, MD, Matthew Dobbs, MD, (Clinic C and Treatment Room) 3:00 Break

3:15 "The Atypical Clubfoot"

-- Jose Morcuende, MD, PhD

3:30 "Brace Compliance with Ponseti Technique"

-- Matthew Dobbs, MD

3:45 "Recognition and Management of Relapse"

-- Jose Morcuende, MD, PhD

4:00 "Short Term Results of Ponseti Technique vs Surgery"

--Frederick Dietz, MD

4:15 Group Questions and Discussion

5:00 Recess

6:30pm Dinner for Participants

**University Athletic Club

SATURDAY, OCTOBER 8, 2005

8:00am Continental breakfast

8:30 "Long Term Ponseti Technique Result"

--Frederick Dietz, MD

9:00 "Long Term Results of Posteromedial Release"

-- Matt Dobbs, MD

9:30 "Worldwide Approach to Clubfoot Treatment"

--Norgrove Penny, MD

10:00 Coffee Break

10:15 Longer Term Follow-up Patient

Parent Testimonials

11:30 Debriefing. Final Discussion and Questions

12:00pm Adjourn

GUEST FACULTY

Norgrove Penny, MD

Associate Professor

University of British Columbia

Vancouver, Canada

Matthew Dobbs, MD

Assistant Professor Shriners Hospital for Children St. Louis, MO

UNIVERSITY OF IOWA CARVER COLLEGE OF MEDICINE FACULTY DEPARTMENT OF ORTHOPAEDICS AND REHABILITATION

Stuart Weinstein, MD
Professor
Ignacio Ponseti, MD
Professor Emeritus
Jose Morcuende, MD, PhD.
Assistant Professor
Frederick Dietz, MD
Professor

A copy of the brochure for the meeting can be seen at http://www.medicine.uiowa.edu/cme/pdfs/ponseti%202005.pdf

Here is some information on each of the presentations. I didn't keep notes except on Matt Dobbs' presentation and I missed a couple of talks. I hope that my information is accurate in what each presented.

8:45 "Kinematics of the Subtalar Joint: Why the Ponseti Method Works"

--Norgrove Penny, MD

Dr. Penny pointed out that Dr. Ponseti has stated for many years and repeats in his book that his method of manipulation and casting was based on a proper "understanding of the functional anatomy of the normal foot as well as of the clubfoot. Without this understanding, it is impossible to alter the forces that caused the deformity and apply the proper corrective manipulations and retaining casts."

Dr. Ponseti has also said that the Kite method attempted to "correct each component of the deformity separately instead of simultaneously" which is not how the foot works and is why the Kite method doesn't work.

In Dr. Ponseti's book it states, "All of the components of the clubfoot deformity have to be corrected simultaneously with the exception of the equinus which should be corrected last." Quotes from Dr. Ponseti are from his 1996 book "Congential Clubfoot, Fundamentals of Treatment." . A copy of the introduction to Dr. Ponseti's book with the above quotes and his basic explanation of the historical development of his method can be found in the files section of the nosurgery4clubfoot group site under reference

information. You have to be a member of this group to access the files sections but it's free.

http://health.groups.yahoo.com/group/nosurgery4clubfoot/files/Reference%20Information

Dr. Penny showed in detail how the ankle joint functions and tied it into the reasons why the Ponseti method works. He also showed why the Kite Method of casting (which is what most other casting methods are based on doesn't work).

He said that the motions of the ankle joint are very complex and don't fit into 2 dimensional concepts of motion. The motions of the ankle joint are 3 dimensional. He likened it to the motions of a boat on the ocean. The motions of a boat include yaw, pitch and roll which are similar to the 3 dimensions of motion inside the ankle joint. A web site that shows the motions of a boat can be seen at http://www.boatsafe.com/nauticalknowhow/captpat1.htm

Dr. Penny showed how the Kite method tried to fix each of the problems of the foot in one plane at a time which doesn't work while the Ponseti method addresses all of the 3 dimensional motions of the foot simultaneously which is why it works.

It was a very good visual presentation of the motions inside the foot that make the Ponseti method work

9:30 "Pathology of Congenital Clubfoot:

Errors in the Treatment

--Ignacio Ponseti, MD

Dr. Ponseti explained what is understood about when and how a clubfoot develops in an otherwise normal foot at about 14 weeks of gestation. He explained the complex details which are essentially chapter 2 of his book.

Casting babies. Tenotomy. Many children were presented to show various stages of correction.

3:15 "The Atypical Clubfoot"

--Jose Morcuende, MD, PhD

I am sorry to say that I missed most of this presentation. I believe that this was concerning 18 children who had what they described as Atypical Clubfoot. But luckily, this was also presented at the 2005 AAOS Convention and an abstract of the paper can be seen at http://www.aaos.org/wordhtml/anmt2005/sciprog/270.htm

3:30 "Brace Compliance with Ponseti Technique"

--Matthew Dobbs, MD

Dr. Dobbs presented information on issues relating to brace compliance. He also presented a number of new shoes and bar designs that they have been using to try to make brace compliance better and therefore reduce the risk of relapsing. He said that they have had some good success in reducing brace compliance problems and also reducing relapsing.

3:45 "Recognition and Management of Relapse"

-- Jose Morcuende, MD, PhD

Dr. Morcuende went through what to watch for in relapsing and what to do to avoid relapses as well as treat them should they occur. A lot of his presentation was similar to the information in Dr. Ponseti's 2001 article on relapsing which can be seen at http://health.groups.yahoo.com/group/nosurgery4clubfoot/message/13223 and http://health.groups.yahoo.com/group/nosurgery4clubfoot/message/29612

4:00 "Short Term Results of Ponseti Technique vs Surgery"

--Frederick Dietz, MD

Dr. Dietz presented information about the children that he treated during the 1980's while Dr. Ponseti was retired. At that point in time, they had felt that the Ponseti method could only be used on children prior to about 6 months of age. So when older children had transferred to Iowa in the 1980's who were older than 6 months, usually Dr. Dietz did the surgery for them. It wasn't until Dr. Ponseti came out of retirement in the early 1990's that they began to try to extend the timeframe for which the Ponseti method could be used. I did not write down the details of this presentation.

SATURDAY, OCTOBER 8, 2005

8:30 "Long Term Ponseti Technique Result"

--Frederick Dietz, MD

Dr. Dietz presented information mostly from the 1995 study. "The Treatment of Idiopathic Clubfoot, a Thirty Year Follow Up Note". This study was published in the Journal of Bone and Joint Surgery in 1995 as a 30 year follow-up on the patients from Dr. Ponseti's initial 1963 study of children treated between 1948 and 1956. They are in the process of finishing the 40 year follow-up studies on those same patients that will be published in the next year or so. The results of the 30 year study had been that in the 1995 review "of our patients treated 25 to 42 years ago, it was found that although the treated clubfeet were less supple than the normal foot, there were no significant difference in function or performance compared to a population of a similar age born with normal feet."

This presentation went through how they set up the standards of the 1995 study and the specifics of the results of treatment. Dr. Dietz mentioned that he did not think that this population of patients treated between 1948 and 1956 would be their best outcomes compared to children treated in the more recent past. He said that the reason for this is that in the 50's Dr. Ponseti had only taken the children's feet out about 50 degrees abduction and the time in the brace and compliance with it were not emphasized as much

as now because the method was just being developed. As a result, the 1950's era children had a much greater rate of relapsing and need for the Anterior Tibial Tendon Transfer.

He explained that in 1995, no one else had done a long term outcome study out to a minimum of 25 years and so they had to determine the kinds of things that they were going to study and look for to determine what should be considered excellent, good, fair, poor etc and also figure out a way to compare to a population of normal feet as a constant.

The system they established in 1995 has now been used by a few other groups as a model of methods to study outcomes. One of the things that the U of Iowa has been known for worldwide in many medical specialties is the longest long term outcome studies of different kinds of treatment methods for all kinds of medical issues.

As far at the upcoming 40 year follow-up study, I basically remember that they didn't find much in the way of differences from the 30 year study to the 40 year study on now minimum 35 year to 52 year old outcomes.

9:00 "Long Term Results of Posteriomedial Release" -- Matt Dobbs, MD

This is I think one of the most important studies to be presented at this meeting. Dr. Dobbs at the St. Louis Shriners Hospital did a study of their patients who had surgical posteriomedial releases and were a minimum of 25 years of age. So this study looked at a group of patients similar in age to those studied in Dr. Dietz's 30 year follow-up study that was done in 1995, but with the difference being that they had surgical treatment instead of Ponseti method treatment. Dr. Dobbs used much of the same study criterion and rating scales from Dr. Ponseti's 1980 study to try to show a comparison of treatment methods. In Dr. Ponseti's 1980 study, the ages were from 10 to 27 years with a mean of 18.8 years.

Dr. Dobbs and others said one of the problems in doing this type of study was that most ped ortho's patients typically are only seen by the original doctor until their teens. Also, you have to have a surgeon to agree to do the follow up on their surgically treated patients. He has also had a number of other doctors argue that the surgery done 25 years ago is different than the ones being done now. Dr. Dobbs said that the surgeon who did the surgeries in the study was actually a bit ahead of his time in using circumferential incisions as a part of the Turco method of posteriomedial release and maybe 5 years ahead of what most others were doing. Dr. Turco was from the New England area and had developed a new method of combining the posterior and medial releases called the Turco method.

After 4 years of watching Dr. Dobbs introduce the Ponseti method to the St. Louis Shriners, the older surgeon at Shriners felt that it was important that the study be done and agreed to allow the follow-up to be done on his patients.

Dr. Dobbs said that the study took 4 years to complete at a cost of \$100,000. During the period from 1976 to 1979, they treated 79 patients for congential clubfoot. For different reasons, 17 of the 79 patients were excluded and 62 patients were invited to participate in the study. 45 of the 62 patients agreed to participate in the study. 31 were boys and 14 were girls, 28 were bilateral. They all had a Turco incision of complete soft tissue release (a posterio-medial release).

The study used the Ponseti 100 point index from Dr. Ponseti's 1980 study. They also had a foot function index and used what is called the SF-36 questionaire. They did clinical examinations that included studies of what may have been done in subsequent surgeries, questions on pain and a physical exam. They also did x-ray studies.

The results of the study are as follows: The ages of patients at the time of the study was a mean of 30 years with a range of 25 to 32 years. Age at the time of first surgery was mean of 9 months with a range of 6 to 15 months. 39 of 45 patients had subsequent surgeries. The mean number of surgeries was 3.8 with a range of \pm 1.52 surgeries.

The Ponseti index mean rating of Dr. Dobbs study on surgically treated feet was 65.3 with a range of 30 to 82 points. The Ponseti index rating of Ponseti method treated children in Dr. Ponseti's 1980 study was 87.5 with a standard deviation of 11.7 points and a range of from 50 to 100 points. I do not remember if Dr. Dietz had indicated a Ponseti index rating for the 1995 study and it is not stated that I can find in Dr. Ponseti's book. The rating system for functional results was designed with 100 points indicating a normal foot. The factors included a maximum score of 30 points for questions related to amount of pain with more points meaning no pain and less points more pain related issues, 20 points for questions related to level of activity and 20 points for questions related to patient satisfaction; and 10 points each for motion of the ankle and foot, and position of the heel during stance and gait. The Ponseti index classified scores at excellent from 90 to 100, good from 80 to 89, fair from 70 to 79, poor for less than 70 points.

In Dr. Dobbs Surgical treatment study, 68% reported foot pain during normal activities.

In the Foot Function Index, 67% had tenderness to touch, 42% limped while walking, 56% had moderate to severe osteo-arthritis in at least one or more joints. The longer the patients were followed, the worse they did. (Change to: The reported results typically grew in severity from the youngest patients to the oldest patients in the study group???) Doctor Dobbs used the exact words I wrote down and I don't know which way the implication runs. Whether it was the same patients who over time got worse or the older patients in the study were worse than the younger patients. Dr. Dobbs said that the study should be published in the next year or so.

About this point, at the end of Dr. Dobbs' presentation, one of the older doctors who was visiting Iowa stated that 3 years before he died, Dr. Turco had presented, but didn't publish, that his patients who had Turco method surgeries had done poorly. Dr. Turco's surgical method was developed during the 1950's and he published a 15 year outcome

study on his method in 1979 and other papers in 1974, 1981 and 82. Dr. Vincent Turco died at age 82 in 1998 in Providence, Rhode Island.

After this, Dr. Ponseti stated that when he came to the U of Iowa in 1941, one of his first assignments had been to study the long term outcomes of clubfoot patients who had mostly been treated surgically. He said that the outcomes he saw and studied were very poor and that was what had spurred him to look for a different way of treatment.

In Dr. Ponseti's book, on page 3, he describes those early years. "The treatment of clubfoot has been controversial throughout the last 150 years. When I arrived in the University of Iowa Medical School to complete my training in orthopedic surgery in 1941, the clubfoot was treated by different members of the staff, some with manipulations and plaster casts, others by taping the feet in Denis Browne splints, and still others by using the Kite's (1930) method: removing some wedges from a plaster shoe to correct the components of the deformity. The Thomas wrench was occasionally used to correct residual deformities but finally most feet ended up in surgery. The Brockman technique for the medial release of the subtalar and midtarsal joints was one of the most common operations performed in the department (Brockman 1930). My colleagues and I expanded the medial release operation to include a posterior release and often we made a lateral incision to free the tarsal joints so as to align the tarsal bones with the cuneiforms and metatarsals (Le Noir 1966). Most often this surgery left deep scarring, joint stiffness and weakness. The techniques of treatment and results in our department before 1948 were reported by Steindler, Le Noir, and others (Blumenfeld et al. 1946; Steindler 1950, 1955; Le Noir 1966)."

Dr. Ponseti continues in his book: "Robert Jones from Liverpool and London wrote in 1923 that he had never met with a case where treatment has been started in the first week where the deformity could not be completely rectified by manipulation and retention in two months (Jones 1923). His experience could not be duplicated in our department nor in other clinics I visited, and the results were far from perfect after a very prolonged treatment. Faced with these disappointing results, I set out to discover how a clubfoot could be corrected through manipulation and retention casts in a two-month period after birth, as Robert Jones had claimed."

"From my observations in the clinic and in the operating room, I realized that the orthopedists' failures in the treatment of clubfoot were related, in part, to a poor understanding of the functional anatomy of the normal foot as well as of the clubfoot. Without this understanding, it is impossible to alter the forces that caused the deformity and apply the proper corrective manipulations and retaining casts. I then studied the pathological anatomy of the clubfoot. I dissected several normal feet and three clubfeet of stillborn babies, and obtained serial sections of the two clubfeet of a 17-week aborted fetus. Under (x-rays), I studied the range of motions of the tarsal joints of normal feet and of clubfeet. I trained my fingers to palpate the joints and bones and feel their motions both in normal feet and in clubfeet."

"Based on these studies, I developed and refined a uniform type of treatment in the late forties. By the late fifties, when reviewing our patients for a short term follow-up article (Ponseti and Smoley 1963), 1 knew that I had found the proper approach to the treatment of clubfoot, a treatment that has been followed to the present day in our department with optimum results. Fellows joining our pediatric orthopedic program were impressed to discover the ease with which most clubfeet can be well corrected without surgery in a relatively short time in contrast to the poorer results experienced in other hospitals after extensive manipulations and surgeries." From Dr. Ponseti's book "Congential Clubfoot, Fundamentals of Treatment" 1996. Again, a copy of the introduction to Dr. Ponseti's book with the above quotes and his basic explanation of the historical development of his method can be found in the files section of the nosurgery4clubfoot group site under reference information. You have to be a member of this group to access the files sections but it's free.

 $\underline{http://health.groups.yahoo.com/group/nosurgery4clubfoot/files/Reference\%20Information}$

I had posted a summary of my understanding of the prior 4 Ponseti method long term outcome treatment studies in the past. A link to that message can be found at http://health.groups.yahoo.com/group/nosurgery4clubfoot/message/16462

9:30 "Worldwide Approach to Clubfoot Treatment" -- Norgrove Penny, MD

Dr. Penny presented a great summary of the worldwide issue of 140,000 clubfoot children being born per year with 80% of them in the developing world. He reviewed the Uganda Clubfoot project and other projects in Malawi, Ghana, Nepal, China and training being done by the U of Iowa in many Central and South American Countries. They are working on developing a coordinating center that can help organize donors, countries, doctors, supplies, training materials, etc. with areas that want a program. They are hoping to take it to the World Health Organization and get their endorsement of the general method of conducting it. Having one centralized organization to deal with the administrative stuff will let the doctors deal more with going out and doing it as well as making it easier for more doctors to go.

One of the other great things at the meeting was a parent who is at the Ronald McDonald house with her 3 year 9 month old adopted daughter from China with untreated clubfoot. Dr. Ponseti is treating her and they are hopeful that it will work to at least minimize any possible surgery and push back the time frames of when using the Ponseti method is still possible.

Dr. Penny explained that he and Dr. Mark Sinclair from Germany went to China to begin helping a few centers learn about the Ponseti method. He said that because of China's one child rule, that often children with disabilities are discarded to die while the luckier ones may get to orphanages. They are hopeful that if the Ponseti method catches on there, that more children will survive, be treated and adopted.

One doctor mentioned that she was occasionally brought in to counsel "high risk" pregnancies. She said that when the ultrasounds detect a condition like clubfoot, often the parents are sent to a "high risk" OB doctor who gives them some additional information and offers advice on alternatives, including abortions. This doctor said that the first time it kind of shocked her to go into talk to a pregnant mother who had been told that abortion was an alternative to having a baby with clubfoot. She said she tried to very clinically tell the pregnant mother that most likely her child was normal and that current Ponseti method treatment would mean that the child would be functionally normal in every way. The doctor noted that we need to get this information out to prospective parents so that they don't make assumptions based on outdated and incorrect treatments.

On Saturday, the older children were examined including two - 49 year olds, Ross Snyder and a guy from the Atlanta Track Club, who had both been treated by Dr. Ponseti in the 1950's. Also, a 25 year old 1st year medical student at the U of Iowa that Dr. Ponseti had treated a long time ago. There were also lots of kids from about 7 on down. There were probably about 15-20 who raced and about 50-75 who watched. There had been a Friday night dinner of parents at Bennigans in the Coralville Mall. On Saturday, the parents had snacks in the lounge area of the lower level while the older children were examined and prior to going over to the races. The races were really cute as Dr. and Mrs. Ponseti sat in chairs at the finish line about 25 yards from the start. The races were divided by age groups and were just for fun. There were a couple of children racing in casts that did great. Although the younger children went just the 25 yards, the 5-7 year olds decided that they needed to use the full quarter mile track and they just took off for the full distance once around. The final race was the two 49 year olds who took off and ran the full quarter mile lap around the track.

It was a great 2 days and fun to meet a number of other parents there. I hope that I have communicated what each doctor said accurately. Please remember that I am a parent and not a doctor and this is my understanding of what was said during the meetings. I hope that this information is of help to others.

Martin, Allyson and Joshua (born 3-17-99) http://www.vh.org/pediatric/patient/orthopaedics/clubfeet/egbert.html