

Cosmetic Stature Lengthening Frequently Asked Questions (FAQ's) (Please read this document carefully as it contains the answers to most of your questions)

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Frequently Asked Questions (FAQ's) (bold letters)

Who requests this operation?

The majority of people who seek this surgery are unhappy with their body image. Body image is the way we perceive ourselves. As it relates to height it is the way we perceive our own height and our body proportions (limb length relative to trunk length).

Is there a name for this condition?

The psychologist that I worked with for over 20 years and who evaluated almost all of my patients with this condition between 1988 and 2008, Dr. Walter Windisch, called this condition Height Dysphoria (Dysphoria literally means unhappy, the opposite of euphoria). In other words unhappy with your height. Another term that has been used is one I coined; Height Neurosis.

Some patients also have Body Dysmorphic Disorder. They usually also need psychologic support and medication but may be candidates for this surgery. Psychiatric consultation is warranted in this group.

What is the normal range of adult height in the population?

When assessing distribution of height in the population, we consider the normal bell curve. We divide people by distribution around the mean (average). Normal height is considered ± 3 standard deviations (SD) from the mean. Stature below 3 SD from the mean in persons without a medical condition such as dwarfism or growth hormone deficiency is considered constitutional short stature. A physician defines the normal range of height between the 5th and 95th percentiles. The lower limit of so-called *normal stature* for men is 5'5" (166 cm) and for women is 5'0" (153 cm).

Percentile	SD	Height Women (in)	Height Women (cm)	Height Men (in)	Height Men (cm)
95	+3	68.5	174	74	188
90	+2	67.5	171	73	185
75	+1	66	167	71.5	181

50	Mean	64.5	163	69.5	176
25	-1	63	160	68	172.5
10	-2	61.5	156	66.5	169
5	-3	60	153	65	166

What is the relationship of height to Height Dysphoria

While a person's actual height is related to the condition there is no height threshold under which you cannot suffer from height dysphoria. Most of us would assume that you could only suffer from Height Dysphoria if you are 'short'. The problem is that the perception of who is short varies from person to person. That threshold differs along racial, national and cultural lines : 5'10" is tall in India but short in Holland.

The following anecdote illustrate the point: A man flew all the way from Holland to see me regarding stature lengthening. He was 5'11" tall. He said that since he was a teenager he has suffered from feeling short. He is the shortest male in his family and even his sister is his height. All of his friends are much taller. He reminded me that the Dutch are the tallest people in the world. He is the same height as me. I have never perceived myself as short nor have any of my family or friends. I therefore had difficulty considering him for stature lengthening. I sent him for psychological evaluation. The psychologist report showed he suffered from the same body image problem as all of the other patients we had evaluated. Despite his seemingly tall height he suffered from Height Dysphoria.

When we studied the relationship of starting height to the diagnosis of Height Dysphoria we found that patients starting height varied from 4'10" to 5'11" for males and 4'6" to 5'8" for women. While more of the patients were at the lower end of this spectrum, the fact that some were at the upper end clearly demonstrated that height is not the primary problem. The primary problem is the psyche's perception of height and proportion. We call this body image. Stature Dysphoria is a body image disorder. The patient perceives themselves as short irrespective of the actual height and irrespective of how others see them.

Is there a height threshold above which stature lengthening is not appropriate?

Based on the above findings the answer should be no. I have learned to remove my personal bias regarding height from the evaluation. It is the patient's perception that counts. As regards risks of the procedure they are no greater if you are taller. In fact they should theoretically be less since the percent increase in length of a longer bone is less.

What method do we use for stature lengthening?

At the Paley Institute we use the most cutting edge technology available in the world today. We use implantable limb lengthening for stature lengthening. This involves inserting a telescopic intramedullary nail (tube-like device into the marrow cavity of the bone). The best device available today is the PRECICE from Ellipse Technologies. It is currently the only FDA approved device on the market. The Precice has excellent rate control and patients claim has little pain associated with the lengthening process. The Precice is the only device on the market that has a reverse mechanism. The ability to go reverse is a very important safety feature. We are currently using the Precice 2.1 which is the newest strongest version of this device.

How much height can I gain with the Precice?

Most patients desire 3 inches (7.5cms) of stature gain and some more than that. The The **PRECICE 2.1** (developed through collaboration of Ellipse with Dr. Paley) is now FDA approved for use. The maximum the Precice 2.1 can lengthen is 8cms. Patients who want more than this should consider a second lengthening of the other bone (femur first and then tibia second or vice versa). The total height gain with two lengthenings is up to 14.5cms (8cms in the femurs and 6.5cms in the tibias. (8cms is not well tolerated in the lower leg (tibia) and exceeding 6.5cms can lead to more serious complications). Most patients will not tolerate more than 5cms in the tibias. Of course the cost of two lengthenings is nearly twice that of one lengthening. The Although the Precice can lengthen to 8cms, not every patient can safely achieve this much. We will only allow lengthening to the tolerance of the patients bone and soft tissues.

How long will I be on crutches?

This question is discussed again in a later section. As a quick reference: an 8cm lengthening takes nearly three months to complete the lengthening in the femur and another two months for the bone to heal enough to allow full weightbearing without crutches; total of 5 months. A 5cm femoral lengthening takes nearly two months to complete the lengthening and another month to allow for full weightbearing without crutches. For the tibia a 5cm lengthening takes nearly three months to complete the lengthening and another two months until the bone is healed enough to allow for complete weightbearing without crutches.

What is the safe amount that can be lengthened and why can more length not be done?

The limits of lengthening are the soft tissues. The risk of complications from lengthening increase with increased length. Up to 5cms is a low risk lengthening. Between 5-8cms is medium risk and over 8cms is high risk. For example to achieve

10cms of lengthening it is much safer to lengthen the femur and tibia each by 5cms than to lengthen either bone by 10cms.

What are the advantages of the new Precice2.1

The Precice1 was developed by Ellipse Technology working with a team of orthopedic surgeons including Dr. Paley. Precice1 was designed for the treatment of leg length discrepancy. Dr. Paley was the first surgeon in the US to insert the P1 on Dec. 1, 2011. The Precice2 was spearheaded and developed by Dr. Dror Paley and Ellipse Technologies with the special considerations of the stature lengthening patients in mind. As such it is the first implantable nail to be designed towards the requirements of the stature lengthening patient. The P2 was first used by Dr. Paley in Nov. 2013. The P2 can lengthen up to 8cms for implant diameters of 8.5mms, 10.7mms, and 12.5mms. The P2 8.5mm nail was designed with smaller diameter bones in mind. These are normally found in children, patients with dwarfism and more petite adults (often seen in the bones of many Asian women). The strength of the P2 is up to 4 times stronger allowing for increased weightbearing. Furthermore, the driveshaft connection strength has been increased in strength by up to three fold, which reduced the risk of nail mechanism failure when a patient makes excessive bone, thus preventing the complications of premature consolidation (bone healing) which could arrest the lengthening process. In short, the Precice2 permits greater lengthening with a stronger nail, stronger drive shaft with a larger diameter size range to accommodate all size patients. Most recently the P2 was modified to strengthen the junction between the two telescoping ends of the device. This junction had a special welded connection piece called a crown, which was found to occasionally fail and increased the risk of nail breakage. Dr. Paley identified this weakness and modified the Precice device with the company to make the nail even stronger. The new P2.1 came out in Dec 2014 replacing all previous P2s. This nail is even stronger and more resistant to any failure or breakage.

What is the cost of surgery and physical therapy by the Precice method?

The cost of surgery with physical therapy is \$90,000 (Precice2.1) for bilateral femoral lengthening and \$95,000 for bilateral tibial lengthening (Precice 2.1). For individuals who undergo femoral lengthening followed by tibial lengthening we offer a package price of \$175,000 (Precice 2) if the two lengthenings are performed six or more months apart. If the two lengthenings are staggered two to three weeks apart such that their physical therapy overlaps, there is further cost savings with a total price of \$170,000. In some select individuals we will consider simultaneous femur and tibia lengthening at one surgery for a total cost of \$160,000. Please note that there is a higher risk for fat embolism which can lead to death if both femur and tibia devices are inserted at one time. Although we have never had this complication, it remains a serious theoretical risk. It remains safer to do the two lengthening surgeries on separate dates separated by at least two to three weeks apart.

Are there any additional unexpected costs from the initial surgery?

The pricing for the femur and tibia lengthening includes all additional ancillary procedures such as iliotibial band release and biceps tendon lengthening for femur lengthening and gastro-soleus recession if needed for tibia lengthening. These are done to PREVENT complications. The need for this is determined at the first consultation. Dr. Paley performs three muscle length tests (Ober test, Popliteal Angle measurement, and Ely test) to determine if the iliotibial band-fascia lata, hamstrings, and rectus femoris muscles are too tight. It is not possible to advise a patient of this without seeing them first. The greater the amount of lengthening the more likely is the need for such soft tissue releases. For example, every patient with an 8cm lengthening requires an iliotibial band release while only 50% require this if less than 5cms is carried out. For tibia lengthening if the Achilles tendon is too tight as determined by the Siverskiold test (physical examination) then a gastro-soleus recession is required prior to lengthening. If these structures are tight before surgery and not prophylactically lengthened then muscle/joint contractures that require later more expensive surgery are required (in the lay literature these are referred to as duck ass deformity for tight iliotibial band and fascia lata, and ballerina feet for tight Achilles tendon). Prophylactic anterior compartment release may be done at the time of tibia lengthening. This is done to prevent compartment syndrome. The normal cost of these releases is built into the global fee for the lengthening surgery.

Fortunately complications that require surgery are uncommon. We had two patients in the past 50 that experienced unexpected complications that required additional unplanned surgery to fix. This led to additional costs of about \$30,000 each to fix the complication. This risk is about 4%. We therefore advise to keep about \$30,000 in reserve.

Will insurance pay for cosmetic stature lengthening surgery?

Cosmetic surgery of any kind is not covered by medical insurance. Cost is the number one limiting factor for most individuals seeking cosmetic stature lengthening. Not only will insurance not pay for the surgery, but, if a complication arises that requires additional surgery, insurance will not pay for the costs associated with treating the complication.

Can I get the surgery cheaper in other countries and is it safe?

The Paley Institute is the SAFEST place in the world to have this surgery.

Costs vary by country, center, surgeon and technique. The cost of the device contributes a lot to the cost of the procedure. External fixators while expensive when new can be reused. Therefore the cost of reused external fixators is very cheap. The experience undergoing this surgery with bulky painful external fixators, with all of their complications including infections, joint stiffness, and scars cannot be compared to having the procedure done with the newest, safest technology with few scars and little pain. Many patients choose to go overseas for treatment only because of cost. There are many centers where you put yourself at risk of disaster

and permanent disability. I have had to fix the complications of surgery of many of these patients that had lengthening done overseas. Since this surgery is very lucrative it is open to abuse all over the world including in the US. It is very difficult for the consumer to discern where to go. All limb lengthening surgeons or centers are not the same. Just because it is cheaper does not mean that the patient will get the desired result. I have come to the conclusion that in many cases you get what you pay for. While the cost in the US is higher the safety factor is also proportionally higher. In the past 5 years I have seen and operated upon 20 American and foreign patients who went to have cosmetic stature lengthening at overseas less expensive centers. The cost to reconstruct and 'rescue' their limbs was as high or higher than the cost to undergo the procedure at the Paley Institute in the first place. The final result although improved after I operated upon these patients is not as good as if I had done the surgery originally. Finally, the Precice is the most advanced method and safest method for cosmetic lengthening with less pain and lower complications than other methods.

How experienced is the Paley Institute at limb lengthening?

The Paley Institute is the most Experienced Place in the world to have this surgery.

Dr. Dror Paley is the most experienced limb lengthening surgeon in the world for both stature lengthening and for lengthening for limb length discrepancy. He has performed over 20,000 limb lengthening surgeries since 1986. He has the best track record of success with all types of limb lengthening. This is very important as regards safety.

What is the most important consideration when choosing a limb lengthening surgeon and center?

SAFETY is number ONE. EXPERIENCE is number TWO.

Limb lengthening can lead to many complications. Unlike other cosmetic surgery, limb lengthening can lead to chronic pain and disability. Therefore the most important factor to consider is NOT COST, but rather SAFETY. There are many centers around the world offering stature lengthening at cheaper prices than at the Paley Institute. There are no other centers offering limb lengthening as safely as at the Paley Institute. SAFETY is the most important consideration when choosing where to go. Safety comes from EXPERIENCE and organization. At the Paley Institute we provide the most experienced limb lengthening team in the world with the best safety track record in the world. The multidisciplinary organized team of surgeons, anesthesiologists, medical doctors, nurses, physician assistants, physical and occupational therapists, orthopedic technologists, etc. all of which are dedicated to the limb lengthening process make this process safe, secure and as streamlined as possible.

Can I get financing to help pay for the surgery?

We do not provide financing. However, we can give you the name of one or two financing companies to contact directly. For this info please contact Jessica jsousa@lengthening.us in our financial department who can connect you with financing companies that may be willing to make loans for this type of surgery.

What is covered in the cost of surgery?

- 1) Hospital stay for up to 4 days. There is a surcharge for patients staying longer than this
- 2) All hospital charges relating to the operating room and recovery room
- 3) Implant costs: Two PRECICE 2.1 lengthening rods. Each Precice costs \$15,000 Therefore just the cost of the implants for bilateral implantable lengthening implants is \$30,000.
- 4) Anesthesiologist fees
- 5) Surgeons fees
- 6) Surgery assistant fees
- 7) Hospitalist fees (internal medicine doctor available during the entire hospital stay)
- 8) Radiologist fees (includes their reading fee of all the x-rays)
- 9) All x-rays: up to 11 weeks (surcharge after 11 weeks)
- 10) All office visits: up to 11 weeks femurs; up to 14 weeks femurs plus tibias combined (surcharge after 14 weeks)
- 11) Transportation to and from the office and hospital (5 days per week) for office visits if you stay at one of the approved extended stay hotels (see list below)
- 12) Wheelchair, walker, crutches and bedside commode as needed for post surgery; provided as part of discharge from hospital.

What is covered in the physical therapy fees?

- 1) Daily (5 days per week) one hour of physical therapy at the Paley Institute outpatient rehab center (there is no PT on weekends); up to 11 weeks femurs and tibias (surcharge after 11 weeks); femur plus tibia overlapped up to 14 (surcharge after 14 weeks).
- 2) Transportation to and from the PT center to extended stay hotels on the approved list. PT is located next to our office and on the grounds of the hospital campus.

What is not covered?

- 1) Medications and pharmaceuticals (e.g. pain medicine, anticoagulants, supplements e.g. calcium, bone health now, Vit D)
- 2) Accommodations in West Palm Beach
- 3) Travel to and from WPB
- 4) Travel to the hospital on weekends (although the hotel shuttles will usually provide this for free)

- 5) Food and other supplies during the stay in WPB
- 6) Entertainment or Internet
- 7) Home health aids (nurses, homemaker, etc)

When do I have to send the payment and do I need to leave a deposit to hold the surgery date?

Full payment is due two weeks before surgery or the surgery will be cancelled. Payment can be made by wire transfer or certified check but not by credit card. A non-refundable deposit of \$10,000 is due at least two months before surgery. The deposit can be made by credit card on the phone or by wire transfer. We will not hold a surgery date for more than 3 days without a deposit. Cancellation or change of surgery date by the patient or their family with less than two months notice results in loss of the deposit. The deposit is fully refundable if changes or cancellation of surgery are more than two months before the booked surgery date. The deposit money is part of the total fee and will be credited to the total amount due if it is not lost due to late cancellation or changes. In the case of late cancellation, rebooking of surgery will require new deposit.

How much money should I keep in reserve in case of a complication?

Complications although infrequent can occur and may require surgery to treat and to prevent a negative outcome. An example is premature consolidation of the bone which requires rebreaking the bone (no cases experienced since the P2). Another is nerve entrapment which requires nerve decompression (one case experienced with Precice since 2011). Another is muscle contracture which requires lengthening of muscles, tendons or fascia (one case experienced since 2011). Finally there can be failure of bone healing after the end of the distraction phase requiring repair of nonunion (no cases experienced since 2011). The cost to treat most of these complications ranges from \$12-\$35,000.

What is the likelihood of complications that would require additional surgery?

The likelihood of complications that require additional surgery for treatment is less than 5%.

Can I have lengthening of the femur and tibia together at the same time to save time and expense and to get more length and better proportions?

Lengthening of the femur and tibia allows for greater height gain and better proportions of the femurs and tibias. Lengthening both bones is much more involved and more expensive than lengthening only one pair of bones.

Options	Cost	Maximum Length Gain	Risk
Do the femur and tibia lengthening surgery at the same time in one surgery	\$160,000	5 cm + 5cm = 10cm total	Highest Risk for Fat Embolism & death
Do the femur and tibia lengthening surgery three weeks apart in two surgeries	\$170,000	5 cm + 5cm = 10cm total	More Pain
Do the femur and tibia lengthening surgery a year apart in two surgeries.	\$175,000	8cm + 6.5cm = 14.5cm total	Smallest Risk Greatest Length Gain

Option 1 is the highest risk and I would not recommend it since there is a much higher risk of fat embolism which can even lead to death. I have only performed this option in one patient. Fortunately he did not have any complications.

Option 2 is the safer way of achieving 10cm lengthening in one time by overlapping the two surgeries. The treatment time is a little longer then option 1 by about three weeks. The cost is reduced compared to option 3 since the physical therapy is done at the same time.

Option 3 is the safest way and allows getting the most lengthening since the femur and tibia lengthening are done at different times. It requires more PT and more time. We give a discount on the second lengthening of \$10,000 so the total is lower than the normal femur plus tibia costs.

Although femur and tibia lengthening can be done at the same time we prefer not insert the femur and tibia rods in the same surgery due to the **theoretical** increased risk of *fat embolism syndrome* from reaming the medullary canal of more than two bones at a time. To insert 4 rods at the same surgery would increase the chance of fat embolism and death. We have done this successfully without complication but do not recommend it.

How are the scars from surgery?

We use a minimally invasive method to put the Precice device into the bones. A half inch incision is made at the hip area, and 4 or 5 quarter inch incisions are made on the side of the thigh. These scars are so small they are not very noticeable. Most look no bigger than a mosquito bite.

How painful is limb lengthening?

Immediately after surgery, there is post surgery pain. Most patients have epidural anesthesia or PCA (patient controlled analgesia). We often inject a long acting slow release local anesthetic into the wounds (Exparel) which lasts for 96 hours. These methods offer excellent post operative pain control. Patients are switched to oral pain medication in preparation for discharge from hospital. After discharge all patients receive a prescription for oral pain medication. During the first two weeks after surgery most patients still feel some post surgical pain. Once this is gone the comfort level is greatly improved. The most painful times are during stretching exercises during physical therapy and when going to sleep. We often prescribe some medication to help with sleep. Most patients do not complain of much pain during the daytime. The actual lengthening process of the Precice is usually painless. Most patients have little to no pain during the majority of the lengthening process.

What can I do to prepare for surgery?

a) Education:

- (i) Read all printed materials we provide.
- (ii) Book a consultation and have your questions answered in person
- (iii) Email us any additional questions

b) Physical preparation:

Stretching exercises may help.

For femur lengthening:

- 1) iliotibial band; lie on your side, extend your hip so your thigh is in line with your body and flex your knee. In that position, try and bring the flexed knee towards the ground. Also can do cross leg stretches with the hip straight. These stretches the IT band.
- 2) quadriceps and especially the rectus femoris muscle (bend knee with straightening of hip at same time. Can be done standing pulling foot behind butt and leaning back or kneeling with leaning back).
- 3) Hamstrings: knee straightening while flexing hip.

For tibial lengthening:

- 1) Achilles tendon: heel cord; maximum dorsiflexion (foot up) with full knee extension (straight).

c) Stop smoking and exposure to second hand smoke.

d) Stop all anti-inflammatory meds.

e) Socio-economic preparation:

Organize your life so you can put it on hold for at least three months. You will need to stay in West Palm Beach for at least 9 weeks. You may not be able to go back to work since you will still be wheelchair dependent when you return home for at least one month. Prepare your finances so you can not only afford this surgery but also afford any possible complications from this surgery that can arise. These are not common but can be costly when they do occur.

Be prepared to be single minded and not distracted during the process so you can devote all your energies and attention to the limb lengthening process and rehabilitation.

Visit West Palm Beach and check out where you will stay and the lay of the land. Arrange for someone to come with you or be prepared to hire home health to help you (see separate section on this).

Organize a leave of absence from your job so that you don't feel the pressure of the need to get back to work.

Do I need a psychological evaluation before surgery?

NO

For my first twenty one years I used a psychologist to evaluate all my patients before surgery. After more than 20 years I have gotten fairly good at doing this evaluation myself. The purpose of this evaluation is to make sure we are not operating upon patients with a body dysmorphic psychosis as well as to make sure that patients have realistic expectations and have the proper support required to undergo this procedure.

Do I need to book a consultation before surgery?

RECOMMENDED

Although the information provide via email is very educational, it is preferable to be assesse in person. This helps you become as prepared as possible for the surgery. We have found that patients who do not come for a consultation are not as prepared for the surgery and have much more difficulty when they undergo this procedure.

We make exceptions to this only for patients coming from overseas and book the consultation the week before surgery. Please note that this is not optimal since these patients are less prepared for surgery than those that come in for a consultation well in advance.

What is involved in the consultation and how much does it cost?

The consultation starts with a specialized standing x-ray called an EOS scan. This is a low radiation dose scan of your entire body from head to foot in a biplanar fashion (front and side at the same time). This may be done the night before the consultation if the consultation is first thing in the morning.

You will meet with Dr. Paley's physician assistant (Servando or John) or assistant orthopedic surgeon (Dr. Packer). They will begin by obtaining a detailed history. Your height, weight and arm span will be measured.

Dr. Paley will then come in and evaluate you and your x-rays including a physical examination of range of motion, muscle tightness, etc. He will explain the procedure and advise the best stature lengthening strategy for you according to your specific height increase goals. This will also include consideration of your proportions. Dr. Paley will measure your bone proportions from the EOS scan. The normal proportion of the tibia to femur lengths is 0.80 ± 0.02 . If the ratio is greater than 0.82 your tibias are relatively long compared to the femurs and femoral lengthening may be preferable, while if the ratios are less than 0.78 then tibial lengthening may be preferable. This must be tempered by the amount of lengthening desired since up to 8cm can safely be done in the femurs and usually only 5cm in the tibias. Dr. Paley will go into these and other aspects of lengthening in details and try and answer all your questions.

After the consultation with Dr. Paley the PA or Dr. Packer will stay to answer any additional questions that may remain. They will then take you over to the physical therapy department for a tour. If possible we will try and introduce you to other stature lengthening patients if they are around at the time. We cannot guarantee this as these other patients are scheduled for PT independently of our consultation schedule. We also must request permission from them. We respect and guarantee all patients privacy.

Can I take a tour of the Paley Institute in advance of the surgery?

A tour is part of every consultation. Read above.

How do I book a consultation?

Please call the Paley Advanced Limb Lengthening Institute 844 714-5293 (Toll Free) 561 844-5255 (Main). You may ask for Stacy Rack srack@lengthening.us who makes appointments for new patient consultations in my office.

How do I book a surgery date?

Please contact Rebeca Mones our surgery scheduler. You can either call the Paley Advanced Limb Lengthening Institute 877 765-4637 (Toll Free) 561 844-5255 (Main) or email her directly at rmones@lengthening.us. To secure a surgery date she will ask you to make a deposit on your credit card as explained in a previous section.

How do I protect my privacy regarding my consultation and surgery?

At the Paley Institute we are HIPPA compliant. We cannot and will not release your name or medical information to anyone unless you authorize it. The only exception to this is minor patients

Will I need to come in the day before surgery?

You will have a preoperative visit with the surgery team to go over the consent form and all of the paperwork. You will also have an appointment with our preoperative nurse and anesthesiologist. You can discuss your anesthesia and postoperative pain management in advance of the surgery. You will be given instructions for surgery. You should not eat or drink after midnight and you should come in two hours before your scheduled surgery to the preop area in the Kimmel building on the campus of St. Mary's Hospital, 901 45th St.

How long is the hospitalization?

The hospitalization is usually 3-4 nights. At St. Mary's Hospital this is in a private room on the newly renovated surgical care unit in the Waters 3 Pavilion.

What will happen during the hospitalization?

After surgery you will be taken to the recovery room for an hour or two before going to your room. If you have family or friends, our patient liaison Candice will keep them informed during the surgery and then organize for Dr. Paley to speak to the family after the surgery. She will then bring the family or friends into the recovery room (PACU) after the surgery to be beside the patient. You will have an IV and a Foley catheter (bladder catheter). The Foley will remain in place until the epidural catheter is removed. If no epidural then the Foley can be removed one or two days after surgery. While in hospital you will start on a blood thinner to prevent blood clots. The nurses will make sure you are comfortable and positioned in such ways as to prevent pressure sores. You will have blood test drawn each morning to check your blood level. If your blood level is low a transfusion may be ordered. Each morning the surgical team will come by to check upon you. This will include physician assistants, nurse practitioners and doctors. The epidural or PCA will be discontinued usually after two days. A physical therapist will come each day to start teaching you to move around and to become more independent. You will learn skills such as transfers to and from wheelchair and bedside commode, etc. Once you are mobile enough you will be discharged from hospital with instructions.

Will I require a blood transfusion?

Some patients lose enough blood to require a blood transfusion before surgery. Therefore autodonation is an option but not required. We use blood from the blood bank if needed. The loss of blood occurs not only during surgery but also after surgery for a couple days. The transfusion if needed almost always occurs one or

two days after surgery. The risks from this are very minimal. Twenty-five percent of our patients require transfusion.

Will I leave the hospital with a wheelchair, walker, and/or crutches?

Yes. You will be given a wheelchair and a walker to take with you. Our case manager Emily Ward will organize all of this for you. Our inpatient physical therapists will teach you how to do transfers from bed to chair to toilet. You will start walking with a walker and later transition to crutches as an outpatient.

What medications will I take after discharge from the hospital?

Blood thinner to prevent blood clots: Xarelto 10 mg daily (approximately \$313.99 per month times 4 months)

Pain medicine (as needed): Percocet 5/325 # 90 pills an 8-10 day supply (approximately \$44.97); we refill this as needed during the lengthening.

Muscle relaxant (optional): Valium 5 mg # 90 pills one month supply (approximately \$24.00)

Where will I stay after discharge from hospital?

There are several options.

- 1) The most common place to stay is at one of our extended stay hotels which are on 45th St. This is a few miles west of the hospital on the same street as the hospital. The cost of stay at these hotels is usually between \$63-99 per night. Cost may vary with season and availability. High season is winter and low season is summer. Please book as far in advance as possible especially in season. Always ask for the Paley rate.

(Shuttle service provided to hospital)
Homewood Suites By Hilton – 561-682-9188
Residence Inn By Marriott – 561-687-4747
Springhill Suites By Marriott – 561-689-6814

(Near Airport, shuttle service not provided)
Doubletree By Hilton – 561-689-6888

- 2) Renting a condominium or house.
- 3) Staying at another hotel.

Is transportation available to and from the hospital to place of residence?

Wheelchair transportation vans are available to take you to and from the hotel to the hospital only if you stay at the extended stay hotels listed above.

How long do I need to stay in West Palm Beach?

You need to stay until the end of the distraction phase (lengthening). The distraction phase length for femur lengthening is one day for each mm of planned lengthening. E.g. 65mms = 65 days. We don't start lengthening for between 0-7 days depending on the age of the patient. Therefore if we don't start lengthening until the 5th day, 70 days for 65 mms and 85 days for 80mms. Tibia lengthening is $\frac{3}{4}$ mm per day compared to 1mm/day for femur lengthening. For tibia lengthening the distraction phase for 50 mm is 10 weeks plus one week before we start lengthening.

Will I need help to look after myself?

Yes you will need help for the first two to three weeks. You either need to come with someone who can help look after you or else you will need to hire a home health aid for the first two to three weeks. We can help you arrange for this. The hourly cost of this is approximately \$18/hr. In the first week after discharge from hospital you will require more hours of help and less help as time goes on. You need to budget for this if you are coming alone. At the very least every one needs help for the first two weeks after discharge from hospital. If you do not have anyone with you this will cost you at least 16 hours a day of help at \$18 per hour (for two weeks the cost can be up to about \$4000).

How much weightbearing is allowed during lengthening?

During distraction the bone ends are held separated by the implantable rod. This rod is secured to the bone by screws at either end. The diameter of the rod ranges from 8.5-10.7-12.5mms. The screws have a diameter ranging from 4-5mms. With enough repeated loading the screws of any implant will bend or break. No implant of any make or design is immune to this. The heavier the patient the greater this risk. This is true of any implantable lengthening nail no matter what the material it is made of and no matter what you are told by the manufacturer or the surgeon.

We permit full WB when we see complete bridging of the bone on the x-ray. At that point the bone is taking the load and protecting the rod. During the lengthening we allow WB using crutches or a walker and unweighting the legs using the arms. The amount of WB allowed depends on several factors: the weight of the patient, the diameter of the rod and the bone being lengthened. For the largest diameter Precice2, 12.5mms, we allow up to 75 lbs (34 kgs) on each leg. This means that when a patient is standing on two legs with two crutches on the ground they can take up to 150lbs or (68 kgs). However, when walking and transferring load from one leg to the other a patient **MUST USE TWO CRUTCHES** on the ground and unweight themselves to the 75lbs (34kgs) weight with each step. Patients must **NEVER** walk with one crutch during the distraction phase no matter how much they weigh. During the consolidation phase the same rules apply until the surgeon increases the WB quota. To know how much WB is being done a patient can stand on a bathroom scale till it reaches the desired e.g. 75lbs number. For the smaller diameter rods 10.7mms and 8.5mms no more than 50lbs (23kgs) is allowed per leg.

Am I allowed to drive?

Patients undergoing implantable limb lengthening can drive once they are not taking narcotics during the day. They do however need to be able to get in and out of the car on their own. Stand up with crutches or walker and transfer to a wheelchair on their own for complete independence. They must learn and be able to do this while abiding by the WB restrictions above.

How often will I have physical therapy?

Daily, 5 days a week for the entire distraction phase. (7 days a week may be available for an additional payment of \$220 per session-please inquire regarding this)

During consolidation phase the patient needs to continue with PT but less often (2-3 days per week). This is usually done closer to home since most patients depart from West Palm Beach to return home. If you plan to stay locally for some time we can arrange physical therapy at our center. The additional cost of this is as noted above and can be paid on a weekly basis.

Daily home exercises are required by the patient throughout both distraction and consolidation phases.

Who does the actual lengthening and where?

The lengthening is done by the patient or their helper at their place of residence during the lengthening. The lengthening is done in $\frac{1}{4}$ mm increments, 4 times a day for the femur and 3 times a day for the tibia. For simultaneous femur plus tibia both bones are lengthened only 3 times a day. The lengthening is done using a special device called the ERC (External Remote Control) device. Our orthopedic technologist trains each patient to do this until they are comfortable using the ERC device. Each patient receive an ERC to take with them. The ERC must be returned at the end of the lengthening to avoid being billed by Ellipse Technologies for this \$10,000 device. There is no charge for the ERC to the patient as long as it is returned.

How often am I seen by the doctor or physician assistant?

Every two weeks at the Paley Institute office.

When will I have x-rays done?

Every two weeks, x-rays of each bone being lengthened are taken.

Once I am done lengthening how soon can I go home?

Immediately.

What is the follow-up after I go home?

Send monthly x-rays to Dr. Paley. The best way is to email these to drorpaley@gmail.com .If you cannot figure out how to email x-rays mail the disc to:

Paley Advanced Limb Lengthening Institute, Kimmel Building, 901 45th St. West Palm Beach, Florida 33407

When can I resume full weightbearing without crutches or a walker?

After reviewing the x-rays, Dr. Paley will email you how they look and whether you can resume full WB. This usually happens after one or two months from the end of distraction. Most patients can return to full WB one month after a 5cm femur lengthening and two months after a 5cm tibial lengthening. Most patients can return to full WB two months after an 8cm femur lengthening.

When can I return to sports?

You have to regain your motion and then your muscle strength before returning to sports. If you work hard at this you can go back as early as six months after surgery. This is individualized by the doctor for each patient.

What are the results from internal lengthening of the femur and tibia?

I have performed implantable lengthening of the femur for 17 years, and have used the Alibizzia, the ISKD and now the Precice. I have the world's largest experience with the ISKD and the Precice devices. To date all of my patients have achieved the goals of treatment and have returned to full activities including sports. An article of our published results is available upon request.

Do I need to have the nails removed?

Yes. All of these nails should be removed. Removal timing is not critical, but most often is done one or two years after the original surgery. The reason to remove the nails is that they are made from titanium and since they have moving parts and generate metal ions over the course of many years. While they are inert and there is no urgency to remove them it is recommended to remove them one or two years after insertion. The Precice also has a rare earth magnet inside. This is sealed from the body inside a waterproof chamber. It is possible that after years this seal could leak and the rare earth magnet would be exposed to body fluids. As such it is preferable to remove this device before this could happen.

What is the cost of removal of the Precice devices?

The cost of removal is separate and is not included in the treatment. The cost of removal is \$17,500 for two femur Precices, \$20,000 for two tibial Precices (including tibio-fibular screws) and \$25,000 for simultaneous bilateral femur and tibial Precice removal. The removal surgery is usually performed at our outpatient Surgery Center .

SurgCenter of Palm Beach Gardens, LLC

900 Village Square Crossing, Suite 100
Palm Beach Gardens, FL 33410
p: 561-429-6880

How soon can I have another lengthening (e.g. both tibias)?

If you choose to have a second lengthening done. An interval of six to twelve months is recommended between lengthenings. It is possible to overlap the femur and tibia lengthenings and this option can be discussed with Dr. Paley.

What are the main potential complications that can occur?

No one wants unexpected problems, complications and costs. For these reasons I am very conservative regarding many aspects of the limb lengthening process. I try and anticipate problems and prevent complications. Many complications lead to additional surgery and therefore to additional costs. The following is a list of some of the potential complications:

Fat Embolism

This is a complication that is very rare and which can be prevented by venting the bone during the reaming (drilling) of the medullary canal of the bone. The way I vent the canal is to drill holes at the planned level of the osteotomy prior to the reaming process. As the pressure builds up in the canal the reamings squirt out the holes preventing fat embolism. Fat embolism can make a patient very sick requiring stay in the ICU. Patients can even die from fat embolism. I have only seen fat embolism twice in my patients. Both occurred more than 10 years ago before I developed a special venting method to prevent this complication. Fortunately both patients recovered uneventfully. **I have never had a patient die from this procedure!**

Deep Vein Thrombosis (DVT) and Pulmonary Embolism (PE)

DVT can occur after any orthopedic surgery or after any fracture. Fortunately we have a very low rate of this complication. Prevention is key. We use anticoagulants after surgery in the hospital and each patient is sent home with a prescription for an anticoagulation drug to be taken until the end of the distraction phase. The cost of this medicine must be borne by the patient and is not included in our cost estimate. While I have seen very few cases of DVT fortunately none of them resulted in PE. PE occurs if the clot dislodges and wanders to the lungs. It can cause shortness of breath, chest pain and even death. This is why we are careful to protect against this.

Taking oral contraceptives and smoking increases the risk of DVT. All of our patients are placed on an anticoagulant, usually Xaralto a new low risk medication. The patient needs to pay for this drug as an outpatient and the cost is not included with the surgery.

Premature consolidation: in this complication the patient bone bridges the gap and prevents further lengthening. Premature consolidation (PC) can occur with any method if the patient is a very rapid bone healer. The patient in these cases is able to make bone faster than the speed at which the bone is being lengthened. The only way to prevent this is to speed up the lengthening intentionally for a week or two. The Precice nail with its rate control allows the surgeon to do this. If premature consolidation does occur it requires an outpatient small surgery to rebreak the bone through a tiny incision. With the ISKD and Albizzia premature consolidation was a well recognized complication due to the lack of control of rate of lengthening. Since lengthening in both of these devices occurred by movement through the osteotomy site and since movement through the osteotomy site can cause pain and muscle spasm, the patients muscles sometimes would prevent the movement and therefore the lengthening from occurring. In other cases both the ISKD and the Albizzia have had broken mechanisms that fail to lengthen during the distraction phase leading to PC. The treatment in these cases was to not only rebreak the bone but also to change the device to a new device. Although in each such case the company provided a new device at no additional cost, the patient still had to bear the cost of an additional outpatient surgery. With the Precice this complication almost never occurs.

Delayed or failure of consolidation: slow or failed bone healing can occur with any lengthening surgery. The best treatment is prevention. We start by identifying factors that may slow healing prior to surgery: low Vit D level, smoking including second hand smoke, anti-inflammatory medicine use, anti-convulsant medication use, menopause, other medication use e.g. acutane,. We also recommend supplements to help the bone heal faster (www.bonehealthnow.com; order Silical, Silical2 and Boost). If a patients blood work shows a low Vitamin D, then Vit D supplements are recommended. We try and identify these factors in advance of surgery. In surgery we there are several steps that help maximize the bone healing: e.g. we use a technique originally developed by Dr. Paley in 1990 to allow bone marrow to surround the area of the bone cut. This is done by making drill holes at the level of the planned osteotomy before reaming the bone. Stable fixation is also important so the choice of nail length and diameter are important as well as the level of the osteotomy. Even the type of osteotomy affects the rate of bone healing. Cutting the bone with multiple drill holes and an osteotome is the most minimal invasive way while using an intramedullary saw or performing an open osteotomy have higher failure rates. All of these are surgeon controlled parameters and are based on surgeon knowledge and experience. Choosing the wrong level or method of osteotomy or the wrong diameter or length of implant can significantly impact the result. The next most important factor is the rate of distraction. Lengthening too quickly can lead to delay or complete or partial failure of bone formation. Too rapid

distraction was the most common cause of poor bone formation with the ISKD. This is not a problem with the Precice since it has complete rate control. Poor bone healing can be recognized during the lengthening process. Once it is recognized the rate of distraction should be slowed. With the Precice the lengthening can be reduced to any level or even stopped. If despite these changes the bone healing remains poor, the lengthening can be reversed until better bone formation is seen. The bone can then be relengthened. This can only be done with the Precice. Going reverse is not possible with the ISKD, Albizzia or the Fitbone. This is a huge advantage that is possible with external fixation and now with the Precice.

If delayed healing occurs despite all of the above steps we start using the accordion technique. Using an ERC device the bone is compressed one mm per day and distracted one mm per day. This cycle is repeated several times a day. This stimulates bone healing and avoids the need for surgery.

Delay or failure of bone formation can delay weightbearing and increase the period of disability and recovery. Furthermore it can lead to the need for surgery to get the bone to heal. Such surgery requires a bone graft and is not a small operation and can be quite costly. Therefore having a device like the Precice that can prevent or treat the problem is a major advance.

Nerve injury: nerve injury can occur with any lengthening surgery but is usually uncommon if the rate of distraction does not exceed 1mm per day and if the amount of lengthening is restricted. Rate control is the most important factor to prevent nerve damage. Recognition of nerve symptoms is important. The lengthening should be stopped or slowed in such cases. If any motor symptoms (weakness or paralysis of muscles) occurs a nerve decompression should be done as soon as possible. This is a small outpatient surgery. In most cases it is the peroneal nerve that gets into trouble. It is important that the surgeon know how to decompress this nerve to prevent foot drop. Delay in decompression can lead to permanent foot drop. With the Precice and complete rate control, nerve injury is very rare and greater lengthening can be performed safely.

Muscle contractures: muscles normally get tight with lengthening. A muscle contracture occurs when a muscle gets tight enough to prevent a joint from moving through its entire range of motion. To prevent muscle contractures physical therapy (PT) is essential. The patient should do daily stretches of the muscles and joints at risk. E.g. knee joint and quadriceps muscles for femur lengthening and ankle joint and Achilles tendon for tibial lengthening. In addition to formal PT the patient should do their own stretches at home several times per day. PT is essential to the lengthening process. It is however expensive. I will not consider doing a lengthening if a patient is not willing to do PT. This is not an option for reducing cost. The controlled rate of lengthening with the Precice makes the risk of muscle contractures and muscle spasm less. The Precice does not obviate the need for PT. Maintaining range of motion and preventing contractures during lengthening decreases the rehabilitation time to return to normal function after the lengthening is finished. A fixed contracture of the knee or ankle can lead to disability and the

need for more prolonged PT and the expenses associated. If despite additional PT the contracture does not resolve additional surgery to lengthen muscles, tendons and fascia may be required. I try and anticipate this and prophylactically lengthen certain soft tissue structures to prevent contractures (e.g. iliotibial band). If this is done at the initial surgery the additional cost is small. If soft tissue lengthening surgery is required at a later date the cost is much higher since one also has to pay for the hospital costs.

Fibular complications: with tibial lengthening the fibula has to be lengthened too. The implantable lengthening device only lengthens and fixes the tibia. The fibula has to be fixed to the tibia so that it lengthens together with it. If the fibula is not fixed or not fixed adequately it will not lengthen as much as the tibia and will lead to severe consequences including subluxation and arthritis of the ankle and flexion contracture of the knee. The method of fixation is critical. Many surgeons only fix the lower end of the fibula to the tibia. This can lead the fibula to prematurely consolidate and to pull down and dislocate from the tibia at its upper end. It is important to fix the fibula at both ends. With external fixation the fibula can be fixed with the wires of an external fixator. With implantable lengthening the fibula must be fixed with screws to the tibia; one screw at the upper end and one at the lower end. The angle, level, position, diameter, and type of screw are all important. E.g. a common mistake is to put the screw in horizontally between the two bones. This is not strong enough to prevent the fibula from pulling away from the tibia at the ankle. This is very subtle and even a few millimeters of difference in length of the fibula at the ankle lead to short term and/or long term consequences for the patient. Removing a segment of the fibula to prevent the fibula from not separating is another common method that should be abandoned. It leads to a nonunion of the fibula which can lead to a stress fracture at a later date in the tibia. Furthermore it usually does not prevent the fibula from pulling away from the tibia. Therefore fibular complications have nothing to do with the type of implantable lengthening device but rather with the method the surgeon chooses to fixate the fibula to the tibia and the method of cutting the fibula bone.

Historical perspective on implantable limb lengthening devices:

I have been performing Limb Lengthening Surgery since 1986. The two main indications for such surgery are limb length equalization for limb length discrepancy (LLD) and stature lengthening for short stature. Since 1986 I have performed over 17,000 limb lengthening surgeries. This is more than any other surgeon in the US or the world. The majority of these surgeries were for LLD. Over 1500 were for short stature related to dwarfism and cosmetic reasons.

Dr. Paley's history with cosmetic lengthening for stature is as follows:

Dr. Paley started with the *Ilizarov method* for lengthening of both tibiae in 1987 and soon after switched to the *lengthening over nail* method he had developed in 1990. Although his results were excellent, the scars, the pain, the suffering, the pin site infections were not conducive to a cosmetic procedure.

He sought a fully implantable lengthening solution. When the *Alibizzia nail*, developed by Guichet became available he worked with the French company that made the nail to develop a tibial lengthening Albizzia for stature lengthening. He started using this in 1996. The severe pain experienced by patients from the 15° rotation of the thigh through the break in the bone, as well as several implant failures lead him to stop using this non-FDA approved device. In 2001, when the *ISKD*, developed by Dr. Cole was approved by the FDA and marketed by Orthofix became available, Dr. Paley was the first surgeon after Dr. Cole to implant this device. This device turned out not to be a great device for stature lengthening. Although he performed over 350 ISKD implantable limb lengthenings, more than anyone in the world, the lack of rate control with this device caused many complications. The other problem with the ISKD was frequent malfunction of the mechanism, which for unexplained reasons would fail to lengthen in the middle of the distraction phase. This lead to increased numbers of procedures to treat complications. For stature patients this also meant increased costs. Despite this his final results were excellent in almost every patient with the ISKD. The ISKD, the Albizzia and the Fitbone are all contemporary devices. They can all be considered first generation lengthening nails. They all suffer from significant mechanical and other problems.

The first second generation device on the market is the Precice. On December 1, 2011, Dr. Paley implanted the first 3 Precice nails in the United States. By November 2013, he performed over 155 Precice cases. At present he has implanted more than 400 Precice nails (more than any other surgeon worldwide). These cases include femoral, tibial and humeral lengthening with the Precice. The results with this device were excellent. The most serious shortcomings of the device were breakages of the nail or its lengthening mechanism that occurred mostly with the P1 and to a much lesser extent with the P2 and not at all with the P2.1.

Dr. Paley was the first to identify these problems and together with Ellipse Technologies they set out to redesign the nail. The first improved device was the P2 with increased strength of the nail shell by up to 4X and of the mechanism by up to 3X. The P2 was launched in Nov 2013 and Dr. Paley again was the first to use this improved device. This eliminated the problems with the mechanism failures and reduced the breakages significantly. Dr. Paley then recognized a more minor problem in the P2 with fragmentation of a washer that helps connect the telescopic parts of the nail together. This lead to further design changes and the emergence of the P2.1 in Dec 2014. Since then there have not been any further breakages. The improvements have allowed for increased weightbearing.

Here are the links to first PRECICE lengthenings we performed in the news:

<http://newsok.com/edmond-woman-takes-steps-to-lengthen-legs/article/3634689>

http://southfloridahospitalnews.com/page/Dror_Paley_is_First_Surgeon_in_US_to_Perform_Limb_Lengthening_with_New_PRECICE_Remote_Control_Device/7038/1/

<http://abcnews.go.com/Health/york-man-grows-inches-surgery/story?id=15776730>