# DAVID S. FELDMAN, MD

## ORTHOPEDIC SURGERY

Associate Director of the Paley Institute

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### **CONGENITAL PSEUDARTHROSIS OF THE TIBIA**

Congenital Pseudarthrosis of the Tibia or CPT is a rare disorder in which a child is born with a specific bowing of the tibia (anterolateral) and/or a break of the tibia at birth. CPT occurs in about 1 out of 250,000 births. A pseudarthrosis or "false joint" is defined as a break in the bone that fails to heal on its own. In rare occasions, CPT can develop before birth or later in life.

More than 80% of children diagnosed with Congenital Pseudarthrosis of the Tibia are also diagnosed with Neurofibromatosis Type 1 (NF1). Pseudoarthrosis can also occur in other bones such as the radius, ulna and clavicle.

#### **Surgical Treatment**

We at the Paley Orthopedic and Spine Institute firmly believe that every limb with this disorder can be treated, healed and not re-fracture by utilizing a Cross Union Technique. As a result, this condition should never undergo amputation. During the over twenty years I have been in practice, I have seen this condition evolve from one with a nearly 30-40% amputation rate to now where amputation should be a never occurrence.

Treatment involves utilizing pre-surgical Zolendronic Acid intravenously, combined with a surgery that includes: excising all the tissue causing the non-healing bone, freshening the bone edges, placing a very large bone graft from the patient's pelvis (a unique and difficult procedure) between the tibia and fibula, utilizing Bone Morphogenic protein, a periosteal graft from the pelvic lining combined with a growing rod in the bone and a plate to hold it for 6 months. All of this has allowed for complete healing of the tibia in this population. The surgery also allows the ankle to move and preserves the ankle function.

#### **How To Prepare For Surgical Treatment**

In preparation for surgery, you will be scheduled to have Pre-Admission Testing (PAT) completed prior to surgery in the Kimmel building. At this appointment a nurse will perform a blood test and basic vital signs, unless you have already done so with your primary care

provider within thirty days of the surgery date. Specific instructions such as when to discontinue eating and drinking the night before surgery will be discussed. A cleansing soap will be provided and must be used while showering the night before and morning of surgery. You will also meet with anesthesia at this appointment to discuss the process of 'going under' and postoperative pain control options. After your appointment in the Kimmel building, you will go up to the Paley Institute clinic to see one of the physician assistants and Dr. Feldman. They may take another set of x-rays and you will then go over your surgical plan. Please voice any questions or concerns to Dr. Feldman at that time.

It is important that you discontinue all anti-inflammatory medications (NSAIDS), both prescription and over the counter, for two weeks prior to surgery and three months after (unless otherwise instructed). These include: Advil, Aleve, Motrin, Ibuprofen, Naprosyn or Naproxen, Celebrex, Celecoxib, Voltaren, Diclofenac, Toradol, Ketorolac, Mobic, Meloxicam, etc. In addition to NSAIDS, you should also discontinue all blood thinning medications such as aspirin (unless otherwise instructed by your medical doctor or cardiologist), multi-vitamins and any over the counter supplements at least seven days prior to your surgery date. You will be instructed when to resume these upon discharge from the hospital. If you have any questions regarding current medications and whether or not they can be taken prior to surgery, please reach out to Dr. Feldman's physician assistants.

You cannot be exposed to first hand or second hand smoke of any kind for one month prior to surgery and for at least six months following surgery. It is very important that you notify us if you have a personal history or a family history of early cardiac disease, phlebitis, blood clot to the leg or lung (pulmonary embolism) or a history of a bleeding disorder. If you cannot receive blood products due to a religious reason or have an objection to receiving blood products for any other reason, you must also notify us of this before surgery.

In the event that you have any scheduling issues with your pre-operative appointment or surgery date, please contact Dr. Feldman's Executive Assistant, **Jennifer Enterkin** at **jenterkin@paleyinstitute.org** or **(561) 844-5255 ext. 310.** All scheduling for follow up appointments should be referred to **Andrea Mower** at **amower@paleyinstitute.org** or **561-844-5255 ext. 245.** 

Prior to surgery, you may be sent for additional imaging over at St. Mary's Hospital main building. If you need assistance scheduling an MRI, CT Scan or additional x-rays, please contact Andrew Mower. Her email is **amower@paleyinstitute.org** and you can reach her by phone **(561)** 844-5255 ext. 245.

It is preferred that these additional studies be completed at St. Mary's Hospital. If this is not feasible, you may have the study performed elsewhere. In that case, the front office will send you the Rx to do so. If you have the study performed at an outside facility, you MUST bring the study with you on a CD-ROM to your pre-operative appointment or mail it in advance to our office with attention to Shamika Occeus.

The Paley Institute Attention: Shamika Occeus 901 45th Street West Palm Beach, Florida 33407

Should you have further questions regarding imaging studies or how to mail in a copy of the disc, you can reach out to **Heather MacDonald** at <a href="macdonald@paleyinstitute.org">hmacdonald@paleyinstitute.org</a>.

For a faster process, you may upload the images yourself to the **My Medical Images** website. Please have the imaging facility place the images on a disc for you so that you can upload them yourself to the My Medical Images website at **www.mymedicalimages.com**. Please notify **Heather MacDonald** at **hmacdonald@paleyinsitute.org** when you are ready to upload your images so she can send you an email with a one-time free upload link. She will need the patient's full name, date of birth, which email address to use to send you the link, and the type of imaging being uploaded (x-ray, MRI, CT, etc). Once you receive the email with the link, follow the prompts to upload your images. There is no need to create an account.

Please keep in mind the following:

- The site is not supported by IE (internet explorer) MUST use Google Chrome or Safari.
- You will need a CD drive/reader to upload the images.
- There is NO need to create an account to use the one time free upload
- However if you choose to create an account, the cost is approximately \$30/year. You may use referral code ORTHOMD for \$10 off for the first year.
- If you have any trouble uploading the images please reach out to My Medical Images support line at (855) 800-2851.
- Once you have completed the process, please once again notify Africa Tyrell who
  will transfer all imaging from the MMI site to our Paley PACS System and notify
  Dr. Feldman's team that they are available for review. You can expect a call or
  email once these images have been reviewed after a few days.

If you have any clinical questions or concerns for the team, please email them and they will respond within a few days.

- David Feldman, MD: dfeldman@paleyinstitute.org
- Aaron Huser, DO: ahuser@paleyinstitute.org
- Tiffany Kochheiser, PA-C: feldmanpa@paleyinstitute.org
- Alyssa Clarke, PA-C: feldmanpa@paleyinstitute.org
- Katie Totten, PA-C: feldmanpa@paleyinstitute.org

If you need assistance with lodging, **Jessie Smith** can assist you with making lodging accommodations. Her email is **jsmith@paleyinstitute.org** or she can be reached by phone at **(561)** 866-6866.

Kristen DeAndrade is Director of Patient Advocacy for Dr. Feldman and Dr. Huser. As a former patient, she is familiar with the surgical and rehabilitative process, and the highs and lows that patients and their families face before, during and after treatment. She has undergone extended limb lengthening, deformity correction, and spinal fusion surgery. Kristen is a direct connection to Dr. Feldman, Dr. Huser and the team and is available to help make the journey as manageable for patients and their families as possible. From a patient standpoint, she can be a valuable resource, please do not hesitate to reach out to her.

Kristen DeAndrade
 Patient Advocate for Dr. Feldman and Dr. Huser
 kdeandrade@davidsfeldmanmd.com

Mia Johnson is the Family Liaison for Dr. Feldman and Dr. Huser. Mia and her husband adopted 4 children internationally with orthopedic needs, who are patients of Dr. Feldman and Dr. Huser. She has thorough experience with limb length discrepancy, cerebral palsy and skeletal dysplasia as well as various orthopedic care procedures, pre-surgical planning and rehabilitation. Mia is available to provide patients and families with resources and advice in regards to lodging, clinic visits, hospitalization and support services.

Mia Johnson
 Family Liaison for Dr. Feldman and Dr. Huser mjohnson@davidsfeldmanmd.com

\*\*Find Mia and Kristen on Facebook, in the group 'Patients and Families of Dr. David Feldman at The Paley Institute (https://www.facebook.com/groups/patientsofdrdavidfeldman) where they can help answer questions and you can connect with other patients and families.

#### What to Expect the Day of Surgery and During the Hospital Stay

A day or two prior to surgery you will be given your arrival time. Please arrive at the Kimmel Outpatient building at the designated time you were provided. Surgery will take place, most often, in the Kimmel building, and you will then be admitted and transferred to St. Mary's/Palm Beach Children's Hospital or Waters 3 (adults aged 18+) unless it is an outpatient procedure. Surgery time depends on the procedure and is often estimated and discussed during your pre-surgical visit. The length of stay in hospital, outpatient versus inpatient, is also discussed at that time.

For children, **Jessie Smith**, our certified Child Life Specialist and Patient Coordinator and **Kaile-Jo Scott**, our certified Child Life Specialist, are available prior to surgery and throughout the entire process to make things a little less scary, easier to understand and even fun. If you have questions or concerns regarding your child's experience with surgery please reach out to them.

- Jessie Smith: jsmith@paleyinstitute.org or (561) 866-6866
- Kaile-Jo Scott: kscott@paleyinstitute.org or (561) 334-9135

If you are an inpatient, after surgery, you will be followed daily by our clinical staff which includes Dr. Feldman, Dr. Huser and other Paley Institute physicians, Tiffany, Alyssa, and Katie or other Paley Institute physician assistants as well as Marcia and Osiris, our nurse practitioners, who work on the floors of the hospital.

Post-operative pain control varies depending on the individual patient. You will receive pain medication intravenously or orally, and will be discharged home with oral pain medication. As you progress in your post-operative recovery, pain medication should be weaned in a tapering fashion. If osteotomies (breaking of the bone) are performed, the ONLY over the counter medication that is acceptable to take for pain relief is Tylenol. Again, the patient must refrain from all anti-inflammatories for approximately the first 3 months after surgery. Over the counter anti-inflammatories are acceptable to take if only soft tissue work was performed, and instructions on which medications are safe to take will be provided to you upon your discharge from the hospital.

If you are an inpatient, on post-op day one, a physical therapist will come to your room to get you mobilized and you will continue to receive physical therapy daily during your hospital admission. The therapist will review proper body mechanics and positioning with you as well how to use any assistive devices such as crutches or a walker. There are, most often, no restrictions with regards to your sleeping position.

All durable medical equipment (DME) such as a walker, crutches, shower chair, wheelchair etc. will be provided to you before you are discharged from the hospital. **Emily Ward** can assist with any DME you will require, her email is **eward@paleyinstitute.org**.

You will be in a cast immediately following surgery. This is most often not removable so as to protect the limb until the osteotomy and bone graft have healed.

If you have a urinary catheter placed during surgery, this will be removed on postoperative day 1 or 2. You may also have drains placed along your incisions which are typically removed just prior to discharge from the hospital.

There is the possibility that you will require a blood transfusion based on the amount of blood loss during surgery, however this is very unlikely. If you or your family has opted to donate blood beforehand, these units of blood will be given to you in lieu of receiving blood from the hospital blood bank. It is best to have a trusted family member or friend donate on your behalf, rather than depleting your blood volume just prior to surgery. Our office can assist with how to donate blood on behalf of the patient; this is done through the **One Blood** donation centers and **Jennifer Enterkin** can assist with coordination of this. She can be reached at **jenterkin@paleyinstitute.org** or **(561)** 844-5255 ext. 310.

What to Expect Once You Leave the Hospital

Outpatient surgery, that is you return home, to a hotel, or to the Quantum House the same day as surgery, is for minor to moderate surgery where hospitalization is not needed. Whether your procedure is inpatient or outpatient, prior to your discharge, you will be given all equipment and pain medication prescriptions. If an elastic bandage feels tight, it can be loosened. Instructions about wound care and showering will be explained before discharge on a case by case basis. Typically, the bandage over your incisions should be left in place until seen at your first follow up appointment. Each operation is different and a protocol will be explained and detailed to you prior to surgery and before you leave the hospital.

Your sutures will usually be absorbable (clear) or more rarely ones that need to be removed (black) in the clinic/office at Paley Institute. If you have absorbable ones, they will dissolve in two to three weeks. You may notice a long piece of clear suture coming from each end of your incision, these strings will be removed for you at your first postoperative appointment. If you have black stitches, these will be removed by a medical assistant in clinic two to three weeks after your surgery date. You will have steri-strips applied to the incision, which is then covered with a waterproof tegaderm dressing. The tegaderm will remain in place for one week. You may remove this tegaderm island dressing and shower on postoperative day seven. You should recover the incision and steri-strips with sterile gauze and paper tape after each shower. Do this dressing change daily until seen in your follow up appointment. The steri-strips will begin to fall off on their own. Please, do not actively remove them. Avoid submerging yourself in a bathtub or swimming pool for four weeks until your incisions are completely healed.

Upon discharge from the hospital, you may begin to follow the prescribed physical therapy regimen given to you by the St. Mary's inpatient physical therapy team. Physical therapy is usually vital to the success of your surgery, allowing motion that was achieved intra-operatively to be maintained post-operatively. After your hospital discharge, you will receive a call from the Paley Institute Physical Therapy department to schedule appointments three to five days a week. It is important that you attend all scheduled physical therapy sessions as well as diligently do your prescribed exercises at home. By the end of week one, physical therapists will have taught you at home stretches to be done daily for the hip, knee, and ankle. These should be done daily in addition to formal PT. These basic stretches will emphasize focus on the motion that was most deficient prior to surgery. For example, if the knees were stuck in flexion prior to surgery, extension will be the focus post-operatively. Please be mindful of the number of physical therapy sessions your insurance company will allow. It is best to contact your insurance company to determine what the coverage is for physical therapy to eliminate any confusion.

Your first postoperative appointment is typically scheduled ten to fourteen days after surgery. At your appointment, often x-rays will be obtained and you will have your first wound check. If you need any splints or braces, you will be fitted for them at this appointment. You will receive splints from occupational therapy the same day, the turnaround time for braces is typically one week.

Pain medication, if it is narcotics, will legally need to be re-ordered with a visit every week.

Your second postoperative appointment will be scheduled at the time of the first. Your second postoperative appointment will be scheduled at the time of the first for approximately four to six weeks after your surgery date.

The timing of your return to school or work will be discussed after your first post-operative appointment and is ordinarily outlined before surgery. We will be happy to provide any documentation or forms required by your school or work. Please contact my administrative assistant **Andrea Mower** who can be reached at **amower@paleyinstitute.org** or **(561) 844-5255 ext. 245** for assistance.

If after surgery you need to reach us for a medical question, we can be reached at (**561**) **844-5255**. There is someone on-call 24 hours 7 days a week. For medical emergencies, please call **911** and go to the nearest emergency room. If you are staying locally, St. Mary's Emergency Room is the most convenient for Dr. Feldman and his team to be involved in your care.