DAVID S. FELDMAN, MD
ORTHOPEDIC SURGERY
Associate Director of the Paley Institute

901 45th Street
West Palm Beach, Florida 33407
https://paleyinstitute.org
Phone: (561) 844-5255
Fax: (561) 844-5245

ARTHROGRYPOSIS PROTOCOL

Arthrogryposis (AMC) affects approximately 1 in 10,000 people. It is characterized as malformed and stiff joints causing limited mobility and function. The contractures are caused by short and abnormally tight soft tissues which prevent the extremities from moving properly.

Arthrogryposis is a condition that may impact the arms, legs and trunk causing them to be weak and stiff. It can also affect the spine. The severity of the condition varies from person to person but encompasses joint contractures that are present at birth. It may be referred to as Amyoplasia or Arthrogryposis Multiplex Congenita.

Most forms of arthrogryposis have no known cause. Less commonly, individuals have a genetic form, such as distal arthrogryposis, that predominantly involves the hands and feet. Another form of arthrogryposis, Escobar Syndrome, has webbing at the joints, called pterygium.

The treatment of arthrogryposis varies based on the individual and their specific deficits. It remains a collaborative effort implementing physical and occupational therapy, casting, and surgical intervention to achieve a desired outcome. These modalities are integrated to improve baseline physical abilities, primarily the ability to ambulate and care for oneself. Treatment at a young age allows children to gain functionality and become stronger, enabling them to have improved joint mobility and function. This provides the foundation for improved long-term outcomes of independence.

There are certain underlying principles of treatment and indications for intervention. We recommend surgery if a significant deformity is present with involvement of the joint leading to a loss of range of motion and function, specifically in the lower extremities which are necessary for mobility. Each surgery is specific to the type of deformity and the location of the deformities. These issues will be discussed at your consultation and preoperative visits. The goal is not just to make a straight limb but for the limb to move with increased range of motion and improved function.

Nonsurgical Treatment

Serial Casting and Achilles Tenotomy

The Paley Orthopedic and Spine Institute uses the Ponseti serial casting method with Ponseti trained physical therapists to treat clubfoot. The Ponseti method of clubfoot correction consists of manipulation of the foot by abducting the foot in supination while applying counter pressure over the lateral aspect of the head of the talus to prevent rotation of the talus at the ankle. All components of clubfoot deformity are corrected simultaneously, except for the ankle equinus. Manipulation is performed for approximately 1 minute followed by application of a well molded long-leg plaster cast. Casts are worn for 3 to 6 days. The cast will be removed in the office and the feet will be manipulated further to achieve even greater correction, and then another cast will be applied. Most children undergo 3 weeks of serial casting with 2 cast per week. However, this may be based on the initial severity and correction achieved with each cast.

Approximately 80% of infants with clubfoot require a tenotomy of the Achilles tendon in order to fully reduce the clubfoot. Depending on the child's age, this procedure may be done by the surgeon either in the office or with sedation in the operating room. A tenotomy would typically be performed after the ideal correction has been achieved with the serial casting.

If a tenotomy is performed, the child will be placed in another cast which will remain in place for 3-4 weeks to allow time for the tendon to heal in its new position. Fully reduced clubfoot should demonstrate 70° of abduction and 15° of dorsiflexion. Once the casts are removed, the child will then be molded for splints or braces to maintain the position of the reduced clubfoot. Ponseti bars and shoes are most often not utilized in the setting of AMC.

To evaluate and schedule a clubfoot serial casting, please contact the **rehabilitation department** at **(561) 844-7878**.

Occupational Therapy, Physical Therapy and Splinting

Occupational Therapy (OT) and Physical Therapy (PT) are multidisciplinary treatments designed to increase function, enhance motor skills and prevent disability in patients with musculoskeletal conditions and injuries.

The therapy the patient receives depends on the type and severity of the patient's condition, and the goals to be achieved. Our occupational therapists take a whole-person approach, working with the entire team at Paley Orthopedic and Spine Institute to ensure all of the patient's healthcare needs are incorporated into occupational therapy and physical therapy.

The occupational therapist and physical therapist may recommend splinting for the patient's hands and fingers, or feet and toes, to help capture and maintain range of motion. The splints are made in the office during an occupational therapy appointment. The splinting regimen may include suggested hours to wear the splints, when to remove the splint for stretching, and multiple visits to receive new splints to help capture any range of motion gains.

To evaluate and schedule clubfoot serial casting or splinting, please contact the **Rehabilitation Department** at **(561) 844-7878**.

Surgical Treatment

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 Africa Tyrell.

The Paley Institute
Attention: Shamika Occeus / (Dr. Feldman or Dr. Huser)
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 **hmacdonald@paleyinstitute.org**.

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**

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.

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

<u>What to Expect the Day of Surgery and During the Hospital Stay</u>

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 may be in a brace or immobilizer immediately following surgery. These are most often removable braces that will protect the limb until more permanent braces are made. You will be molded for more permanent braces at your first post-operative appointment two weeks post-surgery.

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. At times, you may go home with a drain and have it removed a few days later in clinic.

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 with Flexion Deformity Surgery

For correction of flexion deformities of the knees, soft tissue releases are performed in conjunction with surgically cutting and shortening of the long bone to achieve full extension. You will likely be placed in a knee immobilizer postoperatively instead of a cast to prevent stiffness. This should be worn around the clock to maintain extension achieved in the operating room. It can be removed for physical therapy and stretching exercises done at home. The limb will also be wrapped in an ace wrap and webril which can be removed seventy two hours after surgery.

The surgical dressings should be left in place until you are seen at your first follow-up appointment two weeks after your surgery date. At this appointment, the bandages will be removed, your wounds will be checked, and x-rays will be obtained. At this point, you will likely be measured for bracing such as a HKAFO or KAFO which typically takes a week or so to complete.

At four weeks post-op, Dr. Feldman will assess the fit of the braces and another x-ray will be taken to confirm sufficient healing has taken place and you will likely progress to weight bearing as tolerated and can begin gait training in physical therapy.

What to Expect with Latissimus Transfer Surgery

Many arthrogrypotic patients lack the biceps brachii muscle which is necessary to perform so many daily activities, including eating. Dr. Feldman specializes in the transfer of the latissimus dorsi or pectoralis major muscle to this location which can give you increased independence. Prior to surgery, you will have a chest MRI taken to assess the availability of muscle to transfer.

The procedure involves the latissimus dorsi or pectoralis major being transferred and secured with an insertion site mimicking that of the typical biceps brachii. This will enable you to achieve more function of your upper extremity. Primarily, the goal is the ability to actively, independently bring your hand to your mouth without assistance. The muscle transfer is done carefully as to maintain innervation and circulation to the muscle.

Our occupational therapists will create a custom molded splint that will be worn around the clock postoperatively. It is imperative to the success of the surgery that the tendon is given time to heal at the insertion site. To do so, the arm cannot be extended past 90 degrees and no active

motion using the muscle should occur prior to six weeks post-op. Our occupational therapists will work diligently on passive range of motion, training you to fire the muscle and, once cleared by Dr. Feldman, active flexion using the muscle. Active flexion is likely to happen around six weeks post-op.

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.