## Limb Lengthening and Complex Reconstruction Service Hospital for Special Surgery 535 East 70<sup>th</sup> Street New York, N.Y. 10021 www.StatureLengthening.net

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## LENGTHENING FOR CONSTITUTIONAL SHORT STATURE 2020

There is a solution for people with short stature who are deeply dissatisfied with their height. Limb lengthening surgery to increase height can help individuals improve their confidence, body image, and overall happiness.

Lengthening for stature in normally proportioned individuals with short stature but without dysplasia (dwarfism) requires a different strategy for lengthening than in patients with disproportion and dysplasia. Most patients with constitutional short stature (CSS) or low normal stature (LNS) seek only modest increase in stature compared to the extreme amount of lengthening required by patients with dwarfism. In fact, the starting stature of patients with LNS is the final goal of lengthening in patients with dwarfism.

When assessing distribution of height in the population we consider the normal bell curve. We divide people by distribution around the mean (average), and normal height is considered plus/minus 3 standard deviations from the mean. Short stature below 3 standard deviations from the mean in individuals without a medical condition such as dwarfism, growth hormone deficiency etc., is considered constitutional short stature. The lower limit of so called normal stature for Caucasian men is 5'5" tall and for woman is 5'0".

While patients with dwarfism are often treated as children, patients with constitutional short stature or low normal stature are not treated until they have completed growing. Patients with LNS and CSS also do not usually have deformities of the bones. A new fully implanted lengthening nail is available. This approach does not require an external fixator at all. The STRYDE Nail manufactured by Nuvasive Inc. is FDA approved. We use the STRYDE nail which is the third generation and improved implant. My experience with this has been very positive. The lengthening nail is telescopic and lengthens the bone in a very controlled fashion. An external magnet actuates the device and results in 1mm of length per day. This translates into an inch per month. The STRYDE nail is similar in design to the Precice nail except that it is made out of stainless steel and is stronger allowing greater weight bearing than the Precice nail.

The usual goal of lengthening for stature for most patients with LNS is 3.15 inches (8 cm). More than that amount cannot be achieved safely in one pair of bones during one lengthening. For more lengthening one needs to repeat the process in a second pair of bones. The maximum lengthening possible with the STRYDE nail is 8 cm (3.15 inches).

Lengthening of the femurs (thigh bones) is the best first approach since bone healing and recovery is faster and the entire experience is easier than the tibias (leg bones). Furthermore, it looks better in terms of proportion and also scarring. There is also recent evidence that femur lengthening has better long term functional outcome that tibia lengthening.

Most patients are in the hospital 2-3 nights after the procedure. Physical therapy to stretch the hips, knees, and ankles begins in the hospital and continues after discharge as an outpatient. Patients need to have physical therapy for one hour everyday during the 3 months of lengthening. Patients who do best, work diligently at stretching their the hips, knees, and ankles both at home and at therapy. Therapy can be carried out at any therapy center. The patients from out of town can do their therapy in their hometown. Remember you cannot do too much stretching. Some patients are able to do all the exercise on their own with little input from a physical therapist. Most patients do not require more than about two weeks of narcotics after surgery.

Patients are seen in follow up every 2-3 weeks during the lengthening phase. Out of town patients can upload x-rays and be seen virtually on a telehealth visit as well to decrease need for travel. On these visits we check nerve function, measure joint range of motion, exam pin sites and obtain x-rays. Problems are identified and treated and medication prescriptions for pain are written.

One can assume approximately one month of distraction for every inch (2.5 cm of lengthening). Lengthening does not begin until a week after surgery. Therefore 3 inches of lengthening takes about 3 months.

With the STRYDE nail, patients are able to walk as tolerated with crutches or a walker during the lengthening and consolidation phases. Consolidation or hardening of the bone is gradually seen on x-ray. This usually takes about 4 months after surgery. Removal of rods is necessary in the future, and this is done about one year after the procedure, and is an outpatient ambulatory surgery with a very quick recovery. No limitations on weight bearing are necessary at that time.

While there are potential complications of lengthening, our experience has been very smooth and safe (20 years of experience, and thousands of bone lengthenings likely account for that). Joint stiffness is a concern but a rare complication if intense therapy and home exercises are carried out. Deep infection is rare, and would be resolved by removal of rod if it were to occur. Nerve injury is also rare. All patients with lengthening for stature must undergo a psychological evaluation prior to the lengthening. This evaluation is needed before we will agree to offer the lengthening to a patient. Lengthening for stature is considered aesthetic and

will sometimes reimbursed by insurance carriers if there is an associated medical condition or deformity. This is not known until the surgery is planned and preauthorized with you insurance carrier.

Lengthening for stature may be reimbursable by insurance in some cases, especially if there is any evidence of a hormonal or hormone treated related basis for the short stature, or if there is associated deformity.

If not approved by your medical insurance, all fees must be self paid in advance of the services contracted for. We will be happy to prepare a cost estimate for the evaluation, surgery, anesthesia, X-ray, hospital and physical therapy costs. This estimate must be paid in advance prior to the surgery. The approximate current medical costs for bilateral lengthening is about \$125,000 which includes a discounted surgeon's fee, hospital and equipment fees.

Finally the most important issue to consider is that lengthening for stature in any individual over 5 foot tall is primarily for aesthetic and psychological reasons and does not improve function. It does seem to improve body image in patients with what we call short stature neurosis. We have seen a significant improvement in validated SIBID and BIQLI psychological scores after stature lengthening surgery. We Nevertheless, the issue of function is of greatest concern to us. This procedure can possibly damage nerves, muscles and joints. If such damage were to occur it could become irreversible leading to long term problems such as arthritis, limitation of joint motion and pain. Pulmonary embolism and deep vein thrombosis are rare with this surgery, but they can occur and could lead to sudden shortness of breath, chronic leg swelling and even death. While loss of life and limb have never occurred to us with this procedure, one must still weigh the risks of undergoing a major surgical procedure versus the benefits of increasing ones stature by 3 inches. Proceeding with the surgery is a very personal decision.

A psychological evaluation and clearance is needed before being accepted into the program. You will need to make an appointment and see Dr. Ellen Katz Westrich Tel: 212-946-1739 If you are from out of town, you may want to schedule an appointment with her during the same trip to New York. Telemedicine virtual visits are available as well.

We look forward to helping you through this journey.