# Treatment of Apert Hand Syndrome: Strategies for Achieving a Five-Digit Hand

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**Background:** Apert hand reconstruction requires complex surgical planning. The purpose of this study was to describe the authors' 8-year surgical experience with Apert syndrome hand reconstruction, and provide specific surgical strategies for achieving a five-digit hand in Upton type I and II hands.
**Methods:** A retrospective analysis of consecutive Apert syndrome patients who underwent web-space releases between 2007 and 2015 was performed. Demographic, surgical, and outcome data were verified through medical records, clinical photographs, radiographic images, and patient interviews.
**Results:** A total of 41 Apert syndrome patients [23 boys (56.1 percent) and 18 girls (43.9 percent)] have been treated at our hospital since 2007. A five-digit hand was achieved in all patients (100 percent) with Upton type I and II hands, and in eight patients (72.7 percent) with Upton type III hands. A four-digit hand was obtained in three of 11 patients (27.3 percent) with Upton type III hands. Four of 20 patients (25 percent) with Upton type I hands, three of 10 patients (30 percent) with Upton type II hands, and six of 11 patients (54.5 percent) with Upton type III hands required subsequent revision for aesthetic reasons.
**Conclusions:** Upton type III hands have demonstrated higher revision rates than type I and II hands, regardless of whether a four- or five-digit hand is obtained. Treatment strategies for Apert syndrome hands based on hand type are offered to guide four–web-space release in all patients with Upton type I and II hands. (*Plast. Reconstr. Surg.* 142: 972, 2018.)
**CLINICAL QUESTION/LEVEL OF EVIDENCE:** Therapeutic, IV.

Apert syndrome, also called acrocephalosyndactyly, is a rare craniofacial syndrome with an autosomal dominant pattern and a broad clinical spectrum.[1,2] The complex upper and lower limb anatomical deformities in Apert syndrome patients were described by Upton, who suggested a comprehensive clinical classification that may guide therapeutic planning.[3] Although studies and surgeons' opinions showing that a three- or four-digit hand may improve hand function, especially in patients with a tight hand soft-tissue envelope,[4,5] a five-digit hand has been the ultimate goal of the majority of plastic surgeons, without resorting to amputation of one or two digits on each hand (used to release the syndactylies).

Dressing and immobilization protocols have been credited with the mean surgical success rate because they enable skin grafts to take, and decrease the surgical revision rate.[6,7] Chang et al.[8] showed low revision and graft loss rates after cast immobilization was implemented for 2 weeks. Upton[6] also observed persistent web creep in patients who underwent an initial web release early in life (i.e., 3 to 4 months of age). The author attributed this condition to a lack of adequate immobilization and subsequent secondary healing, suggesting that a long and well-padded arm

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cast that extends proximally to the elbow, along with careful follow-up, is what results in a long-lasting satisfactory outcome.[6] However, hyperhidrosis is a frequent finding in Apert syndrome patients[9] that can compromise the skin graft take, leading to infection, dehiscence, and web-space reunion. Surgeons avoid operating in warmer seasons and climates because of the inherent risk of skin graft loss in the early postoperative period.[10] Dressing changes may be necessary in specific countries with consistently hot weather.[4] Our group has been using daily dressings as a customized approach to mitigate the effect of hot weather in our geographic location.

A recent review of the current management of Apert syndrome hands among UK specialists revealed a wide variation in the number of operations (two to four) required to achieve a satisfactory result.[10] Most surgical centers agreed that the number of operations varied by hand type.[10] However, we are not aware of any published studies that have stratified the number of operations based on hand type. We have also anecdotally observed that the revision rate was higher in the most severely affected hands. The purpose of this study is to describe our 8-year surgical experience with Apert syndrome hand reconstruction and to provide specific surgical strategies for achieving a five-digit hand for Upton type I and II hands.

## PATIENTS AND METHODS

An observational retrospective study was performed on consecutive patients diagnosed with Apert syndrome by our craniofacial multidisciplinary team between 2007 and 2015. Demographic (e.g., patient sex and age at the time of the operation), surgical (e.g., techniques used for web-space release, osteotomies, and various aspects of soft-tissue reconstruction), and outcome (e.g., perioperative and long-term complications and need for revision operations) data were verified through medical records, clinical photographs, radiographic images, and patient interviews. Patients who had incomplete medical records and/or postoperative follow-up (<12 months) were excluded from the study. The revision rate was defined as any subsequent operation performed to deepen the commissures. The criterion for revision was based on aesthetic reasoning.

All subjects were enrolled after parental consent was obtained, and the study was performed in accordance with the Declaration of Helsinki of 1975, as amended in 1983. Local institutional research ethics board approval was obtained for this study.

### Surgical Protocol

We determine intracranial pressure using clinical and radiographic examinations (magnetic resonance imaging and computed tomography). Once the risk of immediate intracranial pressure is reduced, we focus our attention on performing the hand surgery before the craniofacial surgery. Because the same surgeon performs Apert syndrome hand and foot reconstructions and craniofacial operations in our hospital, the treatment plan is established in a straightforward manner.

Hand treatment in patients with Apert syndrome is performed as soon as possible. Although we advocate surgery at 4 months of age as being ideal, most of our patients come from all over the country and are much older. Thus, as soon as we evaluate the the patient's craniofacial and neurologic status, we determine the treatment priorities. Apert syndrome hands are classified as Upton type I, II, or III[3] (Fig. 1). Clinical treatment and prognosis are determined by Apert syndrome hand type. Most of our patients presented with symmetrical syndactyly; however, in rare cases, patients presented with a type II hand and a type III hand at the same time. For patients with type I and II hands, we planned a five-digit hand in two operations; in patients with type III hands, a five-digit hand was planned in three operations, or a four-digit hand was planned in two operations.

### Upton Type I Hand

The operation begins with the patient being placed under general anesthesia in the supine position. A full-thickness skin graft is harvested from the lower abdomen in the same fashion and incision design that we routinely use for abdominoplasty.[11] No undermining of the abdominal region is performed.

Initial treatment involves a two-stage release using a straight incision with quadrangular dorsal and volar flaps of equal length to align the web space. Second and fourth web-space releases are performed as early as possible (ideally, at 4 months of age). All cartilage/bone releases are performed with a scalpel and/or osteotomy, respectively, to decrease the phalanx width as necessary. The goal is to obtain the same width for the second, third, and fourth digits. Full-thickness skin grafts are sewn into the web spaces from the fingertip to more proximally toward the quadrangular dorsal and volar flaps. This operation is followed by craniofacial intervention, and the third web-space release is performed along with fourth to fifth metacarpal release as needed to improve

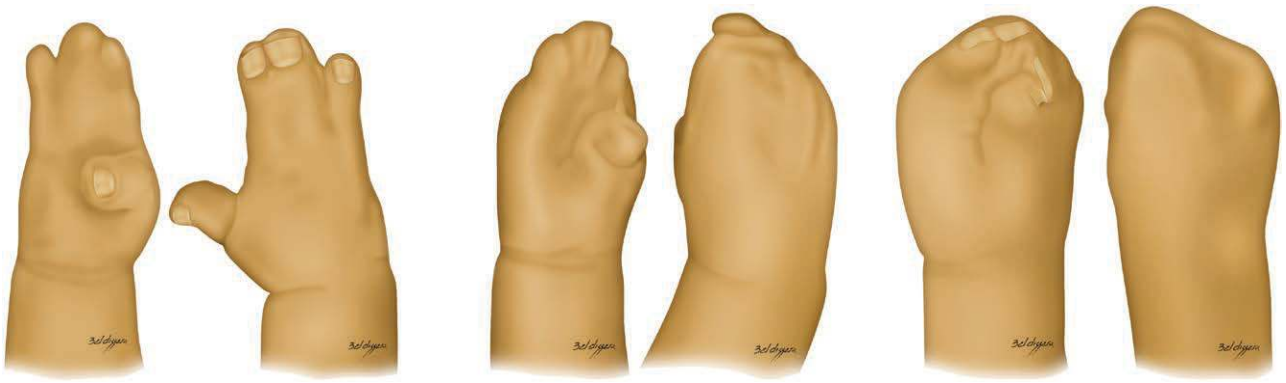


**Fig. 1.** Upton classification. (*Left*) Type I (spade hand) is defined by separation of the thumb from the index finger by a shallow web space. There is a partial or complete simple syndactyly in the ring–fifth finger web space. The transverse metacarpal arch is normal. (*Center*) Type II (mitten or spoon hand) is defined by partial or complete simple syndactyly of the first web space with a separate nail matrix. Concave palm and rotation of the metacarpals and proximal phalanges is also seen. Metacarpal fusion between the fourth and fifth rays is commonly seen. (*Right*) Type III (rosebud or hoof hand) is defined by complex syndactyly with distal synostosis of the phalangeal segments, with a broad conjoined nail. Fourth or fifth metacarpal synostoses are common.

thumb opposition and grasp. Bone release is followed by physical therapy to avoid secondary bone fusion. Thumb lengthening is performed by a delta phalangeal osteotomy and bone graft from the iliac crest region, preferably at 6 years of age or older. A Kirschner wire is used for 2 months to allow bone graft take and osteogenesis.

### Upton Type II Hand

Upton type II hand reconstruction also involves a two-stage release. The first stage releases the second and fourth web spaces, and the second stage releases the first and third web spaces, using quadrangular dorsal and volar flaps. During release of the first web space, the tight investing fascia of the adductor pollicis muscle (transverse and oblique head) is trimmed, and the most distal portion of the muscle is partially released. Thumb lengthening is performed similar to that in the Upton type I hand approach.

### Upton Type III Hand

Operations on Upton type III hands are performed in two or three stages, depending on metacarpal and phalanx fusion magnitude and phalanx width, using the lower abdomen as a donor site for the full-thickness skin graft. The first stage is to release the first and fourth web spaces, allowing border digits to be released first. After the first operation, we can determine whether a four- or five-digit hand can be achieved. In the second stage, we release the second or third web space, depending on the phalanx bone fusion magnitude and phalanx width. If the phalanx width is insufficient to offer a five-digit hand (when compared with the other digits), we release the third web space and leave the second and third digits together. Otherwise, we obtain a five-digit hand in two additional operations. The tight investing fascia of the adductor pollicis muscle is approached in a manner similar to that in Upton type II hands as described previously.[12] The thumb is also lengthened at 6 years of age with a bone graft from the iliac crest.

### Postoperative Care

Our team changes the dressings using dry gauze and a bandage every day, beginning on the third day, and continuing up until postoperative days 21 to 30, depending on the skin graft healing of each patient. The hands are carefully cleaned with antiseptic solution and then dried. The stitches are removed under sedation 14 days after surgery. The family is asked to remain close to our hospital during this period. Afterward, parents are instructed on how to change the web-space dressings (strip bands) for an additional 30 days.

## RESULTS

A total of 41 Apert patients (23 [56.1 percent] boys and 18 [43.9 percent] girls) have been treated at our hospital since 2007. All patients met the inclusion criteria. Stratification by Apert hand severity identified 20 patients (48.8 percent) with type I hands, 10 patients (24.4 percent) with type II hands, and 11 patients (26.8 percent) with type III hands. Two patients had a type II hand accompanied by a type III hand. The mean patient age at the first operation was 25.4 months for type I hands (range, 4 to 120 months), 37.4 months for

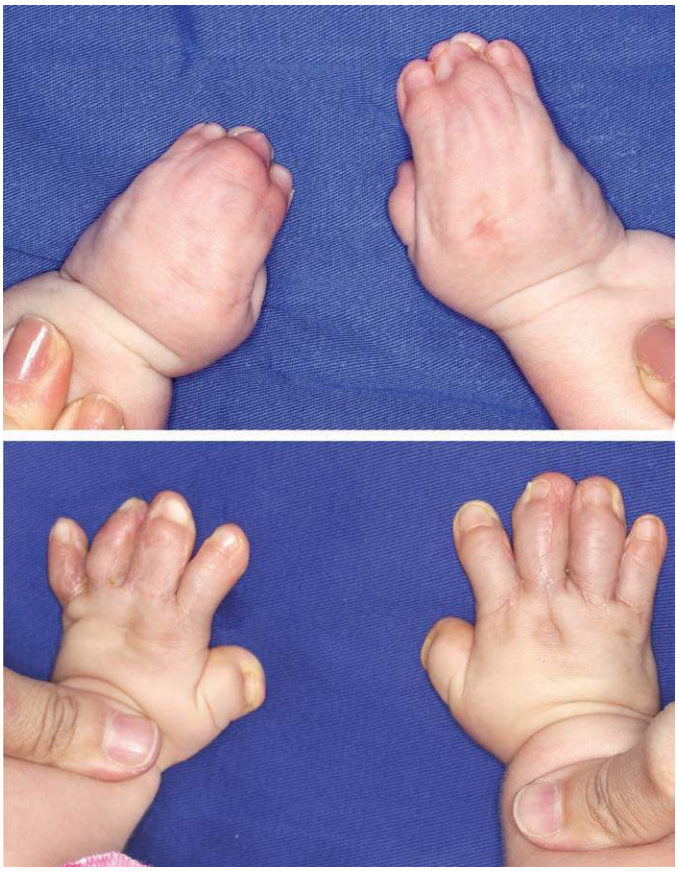


**Fig. 2.** (*Above*) Preoperative photograph of a 4-month-old Apert syndrome patient with Upton type I hands. (*Below*) Postoperative photographs of the same patient with a five-digit hand at 10 months of age.

type II hands (range, 5 to 90 months), and 28.4 months for type III hands (range, 4 to 60 months).

A five-digit hand was achieved in all patients (100 percent) with type I and II hands and in eight patients (72.7 percent) with type III hands. A four-digit hand was obtained in three of 11 patients with type III hands (Figs. 2 through 7). (**See Video, Supplemental Digital Content 1**, which shows the motor abilities of an 11-month-old Apert syndrome patient with a type I hand, ***http://links.lww.com/PRS/C990***. **See Video, Supplemental Digital Content 2**, which shows the motor abilities of a 6-year-old Apert syndrome patient with a type II hand, ***http://links.lww.com/PRS/C991***. **See Video, Supplemental Digital Content 3**, which show the motor abilities of a 14-year-old Apert syndrome patient with a type III hand, ***http://links.lww.com/PRS/C992***.) Four of 20 patients (25 percent) with type I hands, three of 10 patients (30 percent) with type II hands, and six of 11 patients (54.5 percent) with type III hands required revision to deepen the commissure. [**See Figure, Supplemental Digital Content 4**, which shows (*above*) preoperative photographs of a 5-month-old Apert syndrome patient with Upton type I hands. (*Below*) Postoperative photograph of the same patient with a five-digit hand at 8 years of age, after two operations, ***http://links.lww.com/PRS/C993***. **See Figure, Supplemental Digital Content 5**, which shows (*above*) preoperative photographs of a 3-year-old Apert syndrome patient with Upton type II hands, whose initial border digit release using the wrist as a donor site for a full-thickness skin graft was performed elsewhere. (*Below*) Postoperative photograph of the same patient at 4 years of age, with a five-digit hand, after two operations at our hospital, ***http://links.lww.com/PRS/C994***.]

There were no major complications. There was one minor complication at the donor site of a particularly energetic child, in which dehiscence occurred after removal of the stitches. All patients continued follow-up at our hospital with our multidisciplinary team for premidface or postmidface

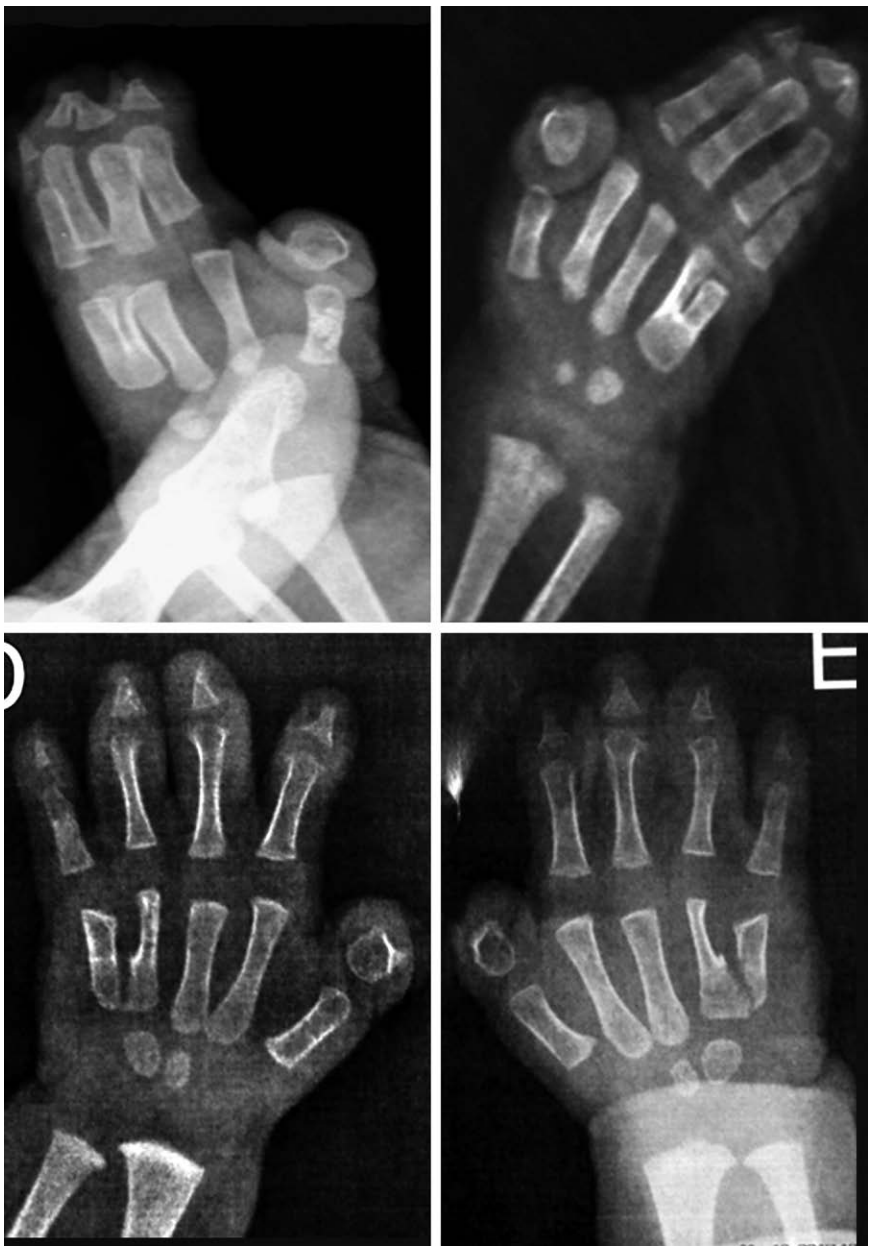


**Fig. 3.** (*Above)* Preoperative radiographs of the same patient as shown in Figure 2. (*Below*) Postoperative radiographs of a five-digit hand after two operations.

advancement with monobloc, monobloc associated with facial bipartition, or Le Fort III advancement (Table 1).

## DISCUSSION

There are differences of opinion regarding the timing of Apert syndrome hand operations. We prefer to operate on Apert syndrome hands earlier in life (at 4 months of age) for mild and moderate Apert syndrome patients. The rationale for starting early is that we have anecdotally observed fewer growth disturbances and reduced secondary deviation of the index finger in patients treated before 1 year of age. In addition, patients are able to pinch and grasp at a very early age because of digit independence, which enables early motor skill development. We have also seen improved quality of life in the highest functioning Apert syndrome patients.[13] However, this hypothesis based on our clinical observation should be validated by further studies, including long-term follow-up, to objectively measure index finger deviation severity and the motor skill repertoire

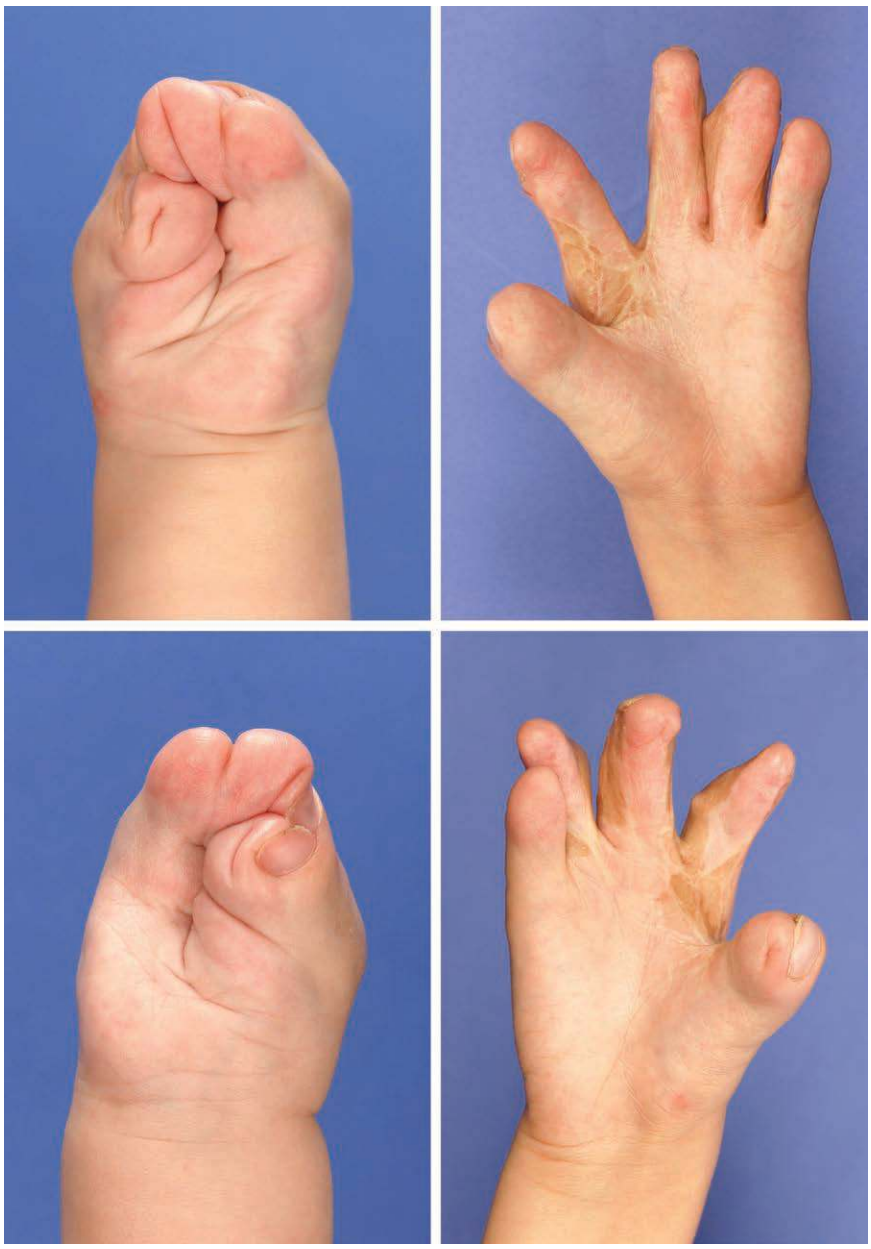


**Fig. 4.** (*Left*) Preoperative photographs of a 1-year-old Apert syndrome patient with Upton type II hands. (*Right*) Postoperative photographs of the same patient with a five-digit hand at 7 years of age.

of hands according to the age at which the operations were performed.

Our data have shown a higher revision rate than previously published data.[4,8] As is often described, the revision rate is considered a parameter of failure regardless of whether a three- or four-digit hand was obtained.[4] The main challenge of Apert syndrome hand reconstruction is managing a tight soft-tissue envelope. A digit amputation generates an additional soft-tissue envelope and may decrease the number of revision operations for the commissures. However, the parameter of success at the first consultation adopted by families of Apert syndrome children (even older patients) has been a five-digit hand instead of fewer operations, and the majority of patients are willing to undergo further refinements to achieve a well-defined commissure and a five-digit hand. Thus, we believe that decreasing the number of operations to obtain a three- or four-digit hand does not outweigh the aesthetic benefit of having a five-digit hand.

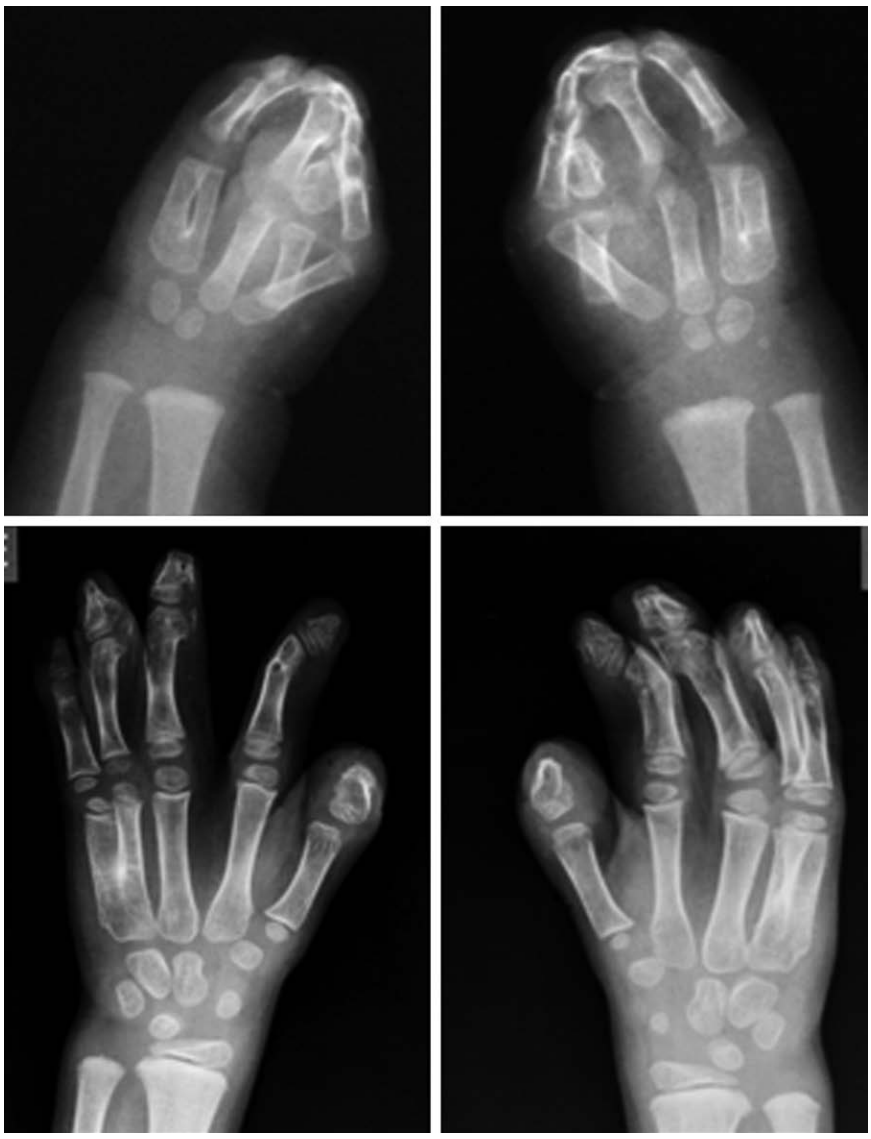


**Fig. 5.** (*Above*) Preoperative radiographs of the same patient as shown in Figure 4. (*Below*) Postoperative radiographs of a five-digit hand after two operations.

In his seminal article, Fearon[7] described six tenets for achieving a functioning and aesthetic five-digit hand: releasing all fingers and toes in two operations; eliminating zigzag incisions by favoring a straight-line incision; avoiding any type of bony amputation to gain a soft-tissue envelope; using dorsal and volar triangular flaps of equal length instead of a long dorsal web space for the lining flap and allowing the distal bone to heal secondarily to decreasing the skin graft size; and improving function in older children using innovative midphalangeal osteotomies.

The use of the straight-line incision results in the most aesthetic hand, because there is no color mismatch of the skin graft in the dorsal region and there is a lower risk for injury to the neurovascular bundle that may jeopardize the four-web space releases. We prefer to use quadrangular combined dorsal and volar flaps of equal length because they provide a wider commissure and reduce the risk of recurrence of the web space. Upton has correlated the use of a long arm cast that extends proximally to the elbow with low rerelease rates, and recommends early cast changes in hot and humid climates.[6] He noted that excessive sweating may result in graft or flap loss. Some surgeons avoid operating in the summer for this reason. In Brazil, temperatures are high year-round, and arm casting resulted in graft loss and infection early on in our series. As suggested by Guero,[4] changing dressings rather than arm casting is recommended for patients in warmer climates to decrease the

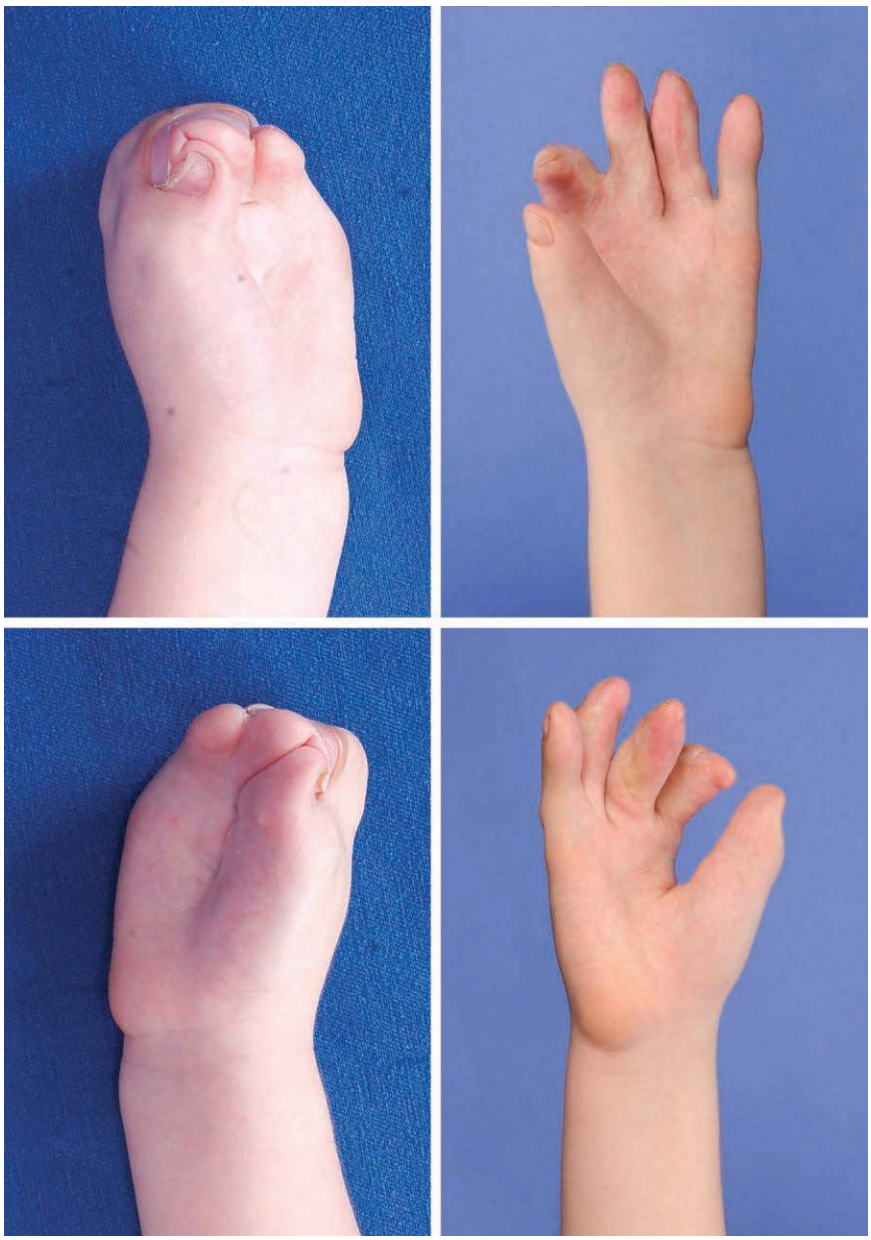


**Fig. 6.** (*Left*) Preoperative photographs of a 3-year-old Apert syndrome patient with Upton type III hands. (*Right*) Postoperative photographs of the same patient with a five-digit hand at 10 years of age.

negative impact of hyperhidrosis on the graft take and healing.

Fereshetian and Upton[12] addressed the first web space with a four-flap Z-plasty in type I and II hands and dorsal rotation advancement flaps in type III hands to obtain sufficient commissure width. For the most severe type III cases, the dorsal flap combined with adductor pollicis muscle release has been a good option for obtaining the first commissure. Our rationale for starting with the border digits in type III hands is that the second and third web spaces in a tight type III hand are difficult to identify. If the first volar incision is not accurately performed, a five-digit hand will not be achieved. Our experience shows that most patients with a severe type III hand will need three or more operations; thus, we do not create the expectation in Apert syndrome families that the goal will be achieved in only two operations.

In type II hands, releasing the second and fourth web spaces before releasing the border digits (consistent with our surgical regimen for

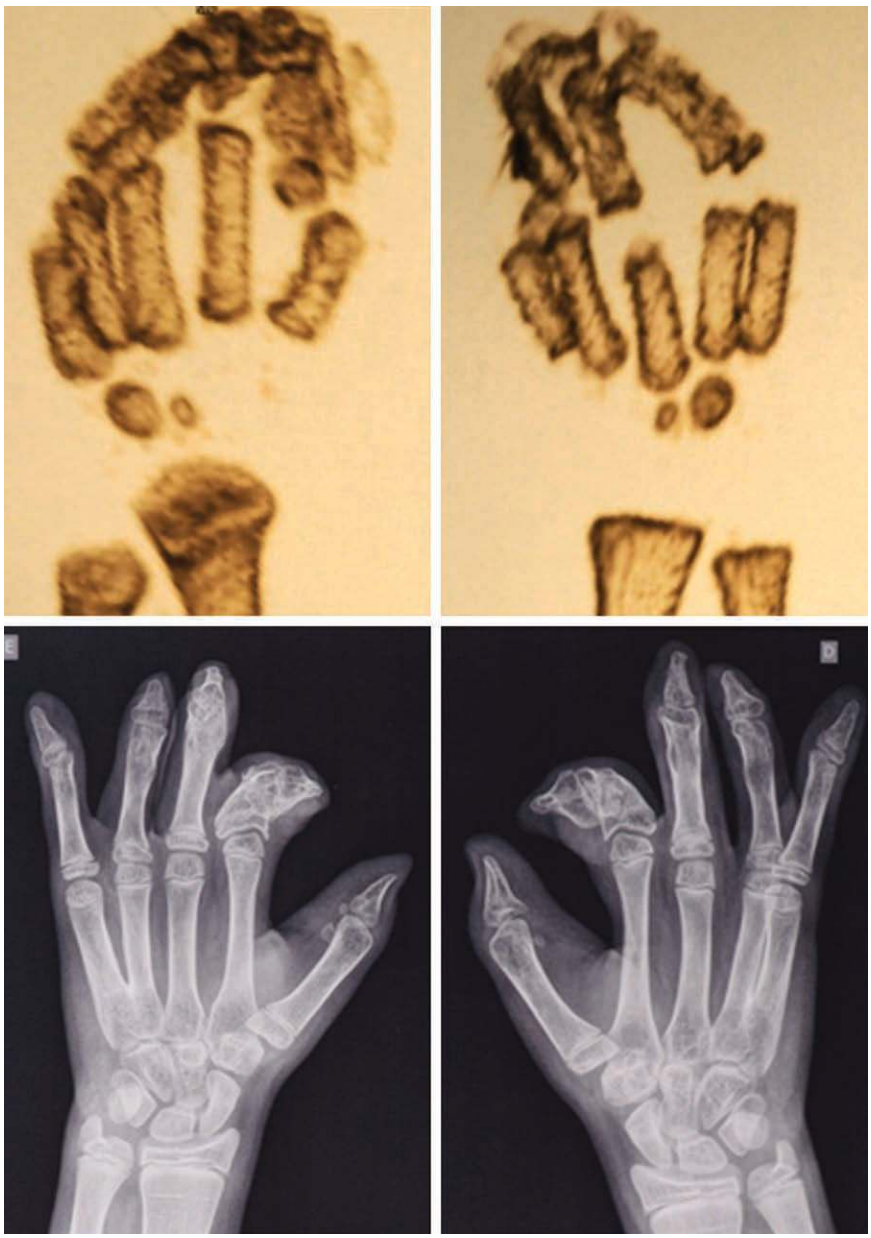


**Fig. 7.** (*Above*) Preoperative reformatted computed tomographic scan of the same patient as shown in Figure 6. Computed tomographic scans in Upton type III hands facilitate a more accurate visualization of the deformity. (*Below*) Postoperative radiographs of a five-digit hand after three operations.

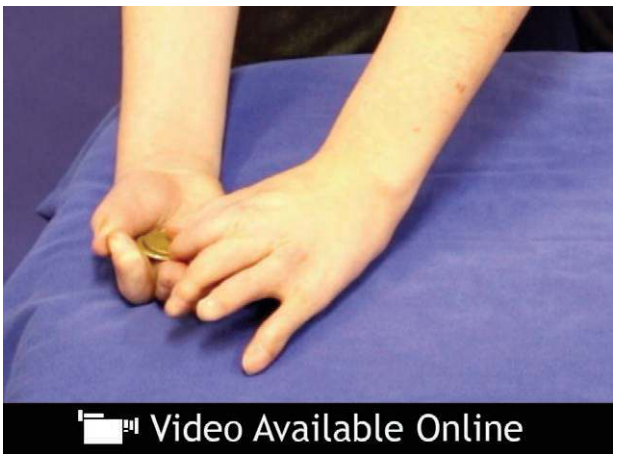
type III hands) increases the probability that a five-digit hand will be achieved in two operations. Releasing the border digits first will require three or more operations to achieve a five-digit hand. Based on our data and current experience, it is possible to anticipate that a five-digit hand will be achieved in all patients with type I and II hands without compromising function, as we previously demonstrated.[13,14] In our series, the revisions were minor (web-space release proximate to the commissure) and usually performed without the need for a skin graft during another intervention of our Apert syndrome surgical regimen (e.g., revision can be performed during palate repair, myringotomy, or feet syndactyly release), to minimize the number of operations. No complete rerelease was performed in our series.

Our focus on an aesthetic hand has led us to be very meticulous with commissures to prevent any minor skin fusion at a more proximal level of the web space, that might ultimately compromise the aesthetics of the hand. We tried to


**Video 1.** Supplemental Digital Content 1 shows the motor abilities of an 11-month-old Apert syndrome patient with a type I hand, ***http://links.lww.com/PRS/C990***.


**Video 2.** Supplemental Digital Content 2 shows the motor abilities of a 6-year-old Apert syndrome patient with a type II hand, ***http://links.lww.com/PRS/C991***.

avoid treating thumb clinodactyly in type I hands early in life because we have seen digit growth impairments induced by open wedge osteotomy and fixation performed at 2 years of age; similarly, we observed facial growth impairments in patients who underwent early frontofacial monobloc advancement. At 6 years of age, substantial growth has been achieved, and an open wedge osteotomy with a bone graft from the iliac crest allows thumb lengthening and helps in the opposition among other digits depending on hand type. In our surgical regimen,[5] we do not advocate the use of bone sacrifice to add a soft-tissue envelope to the hands, so that a five-digit hand can ultimately be obtained in all type I and II hands. The videos shown in our study




**Video 3.** Supplemental Digital Content 3 show the motor abilities of a 14-year-old Apert syndrome patient with a type III hand, ***http://links.lww.com/PRS/C992***.

demonstrate the motor abilities acquired with the achievement of a five-digit hand.

This study is not without limitations, because we did not objectively measure the percentage graft take in relation to hand type, digit growth impairment, and/or deviation in patients operated on before 1 year of age, or the negative impact on neurodevelopment status. Interestingly, we subjectively observed that most graft losses occurred at more distal portions of the digit, and that secondary healing did not result in contractures because of Apert syndrome hand symphalangism. Although we observed that patients who were operated on earlier were less likely to have the digit deviated in the follow-up period, there is no strong scientific evidence to prove this hypothesis; thus, this is merely a senior surgeon's observation, similar to the motor skill repertoire gained after early operations.

Finally, Apert syndrome patients experience a wide range of inherent decline in neurologic status, which might prevent the accurate validation of hand functioning based on a patient-rated outcome questionnaire. Thus, a stratification of the impact of anesthesia, genetic mutation type, intracranial hypertension degree, craniofacial surgery timing, and education quality in the deprivation of neurodevelopment status and functioning in Apert syndrome children has yet to be performed and merits further investigation. Nevertheless, our surgical regimen was developed based on one of the largest single-surgeon Apert syndrome hand experiences worldwide using Upton's hand severity scale. We achieved a five-digit hand in all patients in the current study with type I and II hands. This strategy may help other surgeons plan their Apert syndrome hand treatment regimen.

**Table 1. Characteristics of Patients with Apert Syndrome Distributed According to the Upton Classification of Hand Type Severity**

| Characteristics | Upton Hand Type Severity | | | |
|---|---|---|---|---|
| | I, II, and III (%) | I (%) | II (%) | III (%) |
| No. of patients | 41 (100) | 20 (48.8) | 10 (24.4) | 11 (26.8) |
| Sex | | | | |
| Male | 23 (56.1) | 12 (60) | 5 (50) | 6 (54.5) |
| Female | 18 (43.9) | 8 (40) | 5 (50) | 5 (45.4) |
| Mean age at surgery ± SD, mo | 29.1 ± 28.5 | 25.4 ± 29.6 | 37.4 ± 31.9 | 28.4 ± 23.7 |
| Mean no. of operations ± SD | 2.8 ± 1.1 | 2.4 ± 0.8 | 2.6 ± 0.8 | 3.6 ± 1.4 |
| Mean surgical time ± SD, min | 161.6 ± 44 | 145 ± 44.9 | 163.5 ± 30.9 | 190 ± 40.1 |
| Mean hospital stay ± SD, days | 1 ± 0.1 | 1 ± 0 | 1 ± 0 | 1.1 ± 0.3 |
| No. of digits | | | | |
| Five-digit hands | 38 (92.7) | 20 (100) | 10 (100) | 8 (72.7) |
| Four-digit hands | 3 (7.3) | 0 (0) | 0 (0) | 3 (27.3) |
| Revision surgery | | | | |
| Aesthetic reasons | 13 (31.7) | 4 (25) | 3 (30) | 6 (54.5) |
| No aesthetic reasons | 28 (68.3) | 16 (75) | 7 (70) | 5 (45.4) |
| Surgery-related complications | | | | |
| Hands | | | | |
| Yes | 0 (0) | 0 (0) | 0 (0) | 0 (0) |
| No | 41 (100) | 20 (100) | 10 (100) | 11 (100) |
| Donor-site region | | | | |
| Yes | 1 (2.4) | 0 (0) | 0 (0) | 1 (9.1) |
| No | 40 (97.6) | 20 (100) | 10 (100) | 10 (90.9) |

## CONCLUSIONS

A five-digit Apert syndrome hand is achievable in all Upton type I and II hands. Upton type III hands have higher revision rates than type I and II hands regardless of whether a four- or five-digit hand is obtained.

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## PATIENT CONSENT

*Parent or guardian provided written consent for the use of patient's image.*

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