He underwent a second procedure 19 months after the open reduction internal fixation to remove the plates from the tibia (Figure 9). He remains fully active, using a hinged AFO and no other external support.

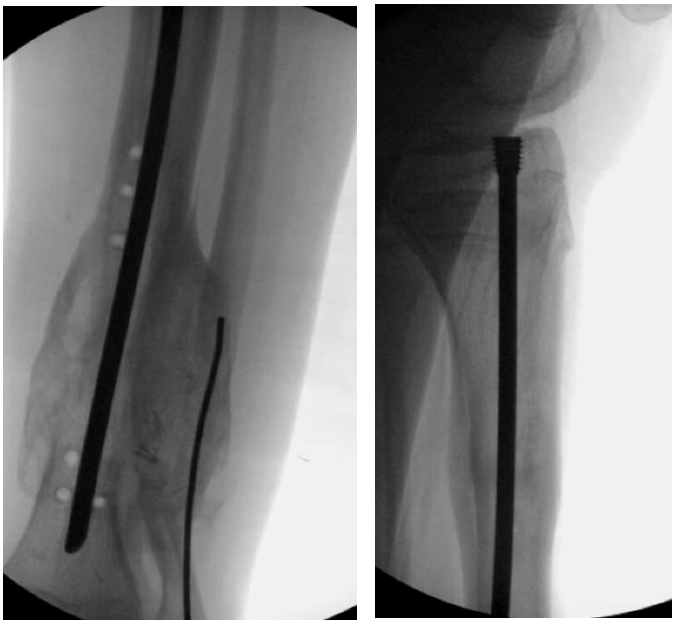

Figure 9. *Nineteen months after the ORIF procedure, the proximal and distal plates are removed.*

Presenter Commentary

JL: *Dr. Herzenberg, thank you for presenting this complex case which demonstrates many of the challenges orthopaedic surgeons face with this condition, including pseudarthrosis, deformity, leg length discrepancy, previous failed attempt at union, and the mental health toll this condition takes on its patients and families.*

In hindsight, if you could treat this patient again from the beginning, would you do anything differently?

JEH: *We would have preferred to receive him earlier in the course of his disease. The initial surgical treatment done at the outside hospital was inadequate and led to psychological trauma and delay in getting satisfactory treatment.*

We use a multimodal approach including bisphosphonate infusion pre-op and at 3-4 months postop, hamartoma resection, transverse osteotomy of the pencil tip ends for internal mechanical stability, autogenous iliac crest bone grafting with a cortical sandwich-style cross-union between tibial and fibula, BMP and cancellous autograft filling the sandwich, and intramedullary stabilization of tibia/fibula. We have also used meshed periosteal grafting from the iliac crest but find that this is less important than the other items listed.

Other authors have recommended the Fassier Duval telescopic rod for fixation of the tibia in CPT. We have observed many complications from this technique, including failure to slide, difficulty to remove the device when attempting to exchange, and bending of the smaller, male end of the device. Additionally, during the index surgery, which is quite complex and lengthy, fiddling with the telescopic mechanism and adding locking wires adds an additional level of unnecessary complexity. Therefore, we no longer recommend the Fassier Duval rod for the initial treatment of CPT. Instead, we use its cousin, the SLIM™ nail. As the tibia grows, the SLIM™ nail can be exchanged as needed. We find that this strategy is easier and less prone to complications, albeit at the cost of perhaps doing more exchanges than would be required if a Fassier Duval rod was used.