

Anti- IL1 therapy for FOP

We are currently recruiting patients with severe Fibrodysplasia Ossificans Progressiva (FOP) who are planning to receive anti-IL1 therapy with anakinra (Kineret) or canakinumab (Ilaris) for a clinical observational study.

- The purpose of this study to observe if anti-IL1 therapies like anakinra or canakinumab can block FOP flare activity such as swelling, pain, decreased movement, stiffness, warmth, and redness and heterotopic ossification
- **Who qualifies for this study?**
 - Diagnosed with Fibrodysplasia Ossificans Progressiva (FOP)
 - Has severe FOP (more than 6 flares per year)
 - Is not responding to standard therapies
 - Whose medical treatment team has recommended that anti-IL1 therapy should be started
 - Age 6-17 years old at the start of the study
- **What does this study involve?**
 - Medical chart review
 - Participation in surveys and video assessments
 - Travel twice to UCSF for clinical assessments
 - Whole body low dose computed tomography (CT) imaging
 - Donation of blood samples
 - This study does not provide the anti-IL1 medication, but will work with the referring physicians to obtain the medications.
- **Accepted participants receive up to \$2000/visit for the 2 onsite visits to UCSF.**

Contact us at: edward.hsiao@ucsf.edu for more information