

FOP Biobank

IFOPA FOP Biobank Inventory as of 6/21/2024

| | | Total Subjects | Minors | Adults | Active Flare | In FOP Registry | Mail-in Collection | Onsite Collection |
|----------------|------------|-------------------|-----------|------------|-----------------|--------------------|-----------------------|----------------------|
| Control | Male | 28 | 5 | 23 | - | - | 5 | 23 |
| | Female | 43 | 3 | 40 | - | - | 7 | 36 |
| | <i>All</i> | <i>71</i> | <i>8</i> | <i>63</i> | <i>-</i> | <i>-</i> | <i>12</i> | <i>59</i> |
| FOP | Male | 21 | 8 | 13 | 6 | 14 | 2 | 19 |
| | Female | 36 | 11 | 25 | 7 | 25 | 9 | 27 |
| | <i>All</i> | <i>57</i> | <i>19</i> | <i>38</i> | <i>13</i> | <i>39</i> | <i>11</i> | <i>46</i> |
| Total | | 128 | 27 | 101 | 13 | 39 | 23 | 105 |

FOP Biobank

IFOPA FOP Biobank inventory by tissue of 6/21/2024

| | | Total | PAXgene | | | | | |
|--------------|--------|------------|-----------|-----------|-----------------|-------------|-----------|---------------|
| | | Subjects | Plasma | Serum | whole blood RNA | Frozen WBCs | Urine | Saliva (gDNA) |
| Control | Male | 29 | 19 | 18 | 11 | 19 | 18 | 27 |
| | Female | 43 | 31 | 31 | 21 | 31 | 33 | 39 |
| | All | 72 | 50 | 49 | 32 | 50 | 51 | 66 |
| FOP | Male | 21 | 9 | 10 | 7 | 9 | 18 | 20 |
| | Female | 36 | 17 | 17 | 12 | 17 | 18 | 23 |
| | All | 57 | 26 | 27 | 19 | 26 | 36 | 43 |
| Total | | 129 | 76 | 76 | 51 | 76 | 87 | 109 |

Serial Samples: (2 or more samples from the same patient with FOP)

| | Total | PAXgene | | | | | |
|-----|----------|---------|-------|-----------------|-------------|-------|---------------|
| | Subjects | Plasma | Serum | whole blood RNA | Frozen WBCs | Urine | Saliva (gDNA) |
| FOP | 8 | 7 | 5 | 3 | 6 | 6 | 3 |

FOP Biobank

- UCSF BSTROnG Biobank (The UCSF Biospecimens and Skeletal Tissues for Rare and Orphan Disease Genetics)
 - Deidentified specimens
 - Blood sample
 - Skin samples (for isolation of fibroblasts)
 - Autopsy specimens (various tissues/organs, fixed in formalin) from patients with FOP
 - Non-commercial use with approval from internal review committee; MTA required
 - Email edward.hsiao@ucsf.edu