



Clinics Serving Children and Adults who have OI: 2016

People who have OI sometimes receive some of their medical care through a special clinic at a large medical center. These clinics go by many names, including “bone dysplasia center,” or “medical genetics clinic.” A clinic offers the benefit of a medical team experienced with OI and able to coordinate care. OI Clinics offer a wide range of services to children and adults. Regular appointments include time with a primary care doctor, orthopedist and members of the rehabilitation team. Additional appointments with other specialists are available as needed. Upon request, the clinic will send reports to hometown doctors if the family lives in a different city. Children and adults who must travel to an OI Clinic also need a local primary care provider who will handle their routine and emergency needs.

This Clinic Directory is one step in the process of locating good medical care. It is the responsibility of parents and adults with OI to verify whether a particular medical team meets their needs. Only by asking questions can you determine if a particular place is a good fit for you. This list is offered as a service. Being listed does not imply endorsement by the OI Foundation. More information about developing a good working relationship with your primary care doctor or orthopedist is available in the OI Foundation fact sheets, Talking with your Primary Care Physician and Talking with Your Orthopedist, available under the Resources tab of this website. For more information about individual clinics in this directory send an email to bonelink@oif.org.

| State | Hospital Name | Clinic Name | Clinic Director | Phone Number | OI Patients Seen Last Year | Services (children, adults, genetics) |
|-------|---|---|--|-----------------------|----------------------------|--|
| AL | University of Alabama Hospital | Bone Dysplasia and Connective Tissue Disorders Clinic | Maria Descartes, M.D. | 205-975-6867 | 50 | Coordination of care between disciplines, Genetics |
| CA | Kaiser Permanente | Skeletal Dysplasia Clinic | Billur Moghaddam, M.D. | 916-614-5177 | 14 | Children & Adults |
| CA | Shriners Hospital for Children- Los Angeles | OI Clinic | Gayle Tyerman, M.D. | 213-388-3151 ext. 251 | 200 | Infants & Children to age 18 |
| CA | Shriners Hospital for Children- Northern CA | | Jennette Boakes, M.D. | 916-453-2000 | 40 | Children to age 18 within general orthopedic program |
| CA | UCLA School of Medicine | Pediatric Bone and Mineral Clinic | Deborah Krakow, M.D. | 310-794-6420 | 30 | Children & Adults |
| DE | A.I. duPont Hospital for Children | Skeletal Dysplasia Program | Richard Kruse, D.O., M.B.A. & Michael Bober, M.D., Ph.D. | 302-651-5916 | ~100 | Children to age 35 |
| FL | Shriners Hospital for Children – Tampa | | Danielle Gomez, M.D. | 813-972-2250 | | Children to age 18 within general orthopedic |

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| | | | | | | program |
| HI | Shriners Hospital for Children – Honolulu | | Craig Ono, M.D. | 808-941-4466 | 30 | Children to age 21 within general orthopedic program |
| IL | Advocate Children’s Hospital | Skeletal Dysplasia Clinic | Brad Tinkle, M.D., Ph.D. | (847) 723-7705 | 6 | Children |
| IL | Shriners Hospital for Children – Chicago | Osteogenesis Imperfecta Clinic | Peter Smith, M.D. | 773-385-5579 | 150 | Children to age 19 |
| IN | Riley Hospital/ Indiana University | Bone Dysplasia Clinic | Bryan Hainline, M.D. | 317-944-3966 | ~60 | Children & Adults |
| LA | Shriners Hospital for Children – Shreveport | | John A Fox, M.D. | 318-226-4296 | 35 | Children to age 18 |
| MD | Kennedy Krieger Institute & Johns Hopkins Medical Center | OI Clinic | Emily Germain-Lee, M.D. | 443-923-2703 | 250 | Children & Adults; referrals to Johns Hopkins Hospital |
| MD | National Institutes of Health | OI Program | Joan Marini, M.D., Ph.D. | 301-594-3418 | >60 | Children accepted into clinical trial and adults being followed post clinical trial |
| MA | Children’s Hospital Boston | Osteogenesis Imperfecta Team | Samantha Spencer, M.D. | 617-355-6021 | 100 | Children to age 21 |
| MN | Gillette Children’s Specialty Healthcare | Orthopedic Clinic | Stephen Sundberg, M.D. | 651-290-8712 | 71 | Children to age 21 |
| MN | Mayo Clinic | Mayo Clinic OI Team | Peter Tebben, M.D. | 507-284-3300 | 45 | Children & adults |
| MO | Barnes Jewish Hospital-St. Louis | Division of Bone and Mineral Diseases | Michael Whyte, M.D. | 314-454-7775 Option #1 | 20 | |
| MO | Children’s Mercy Hospital and Clinics-Kansas City | OI services through Children’s Mercy Kidney Center | Tarak Srivastava, M.D. | 816-234-3392 | 36 | Children to age 18 |
| MO | Shriners Hospital for Children – St. Louis | Research Clinic | Michael Whyte, M.D. | 314-432-3600 ext. 1119 | 50 | Children to age 21 |
| MO | University of Missouri - Columbia | Skeletal Dysplasia Clinic | Daniel Hoernschemeyer, M.D. | 572-882-1351 | 6 | Children to age 18 |
| NE | Children’s Hospital & Medical Center | OI Clinic -- The Tiny Bones Program | Eric Rush, M.D., FAAP, FACMG | 402-955-4199 | 176 | Children |
| NY | NYU Langone Hospital for Joint Diseases | Pediatric Initiative for Bone Health | Patricia Poitevien, M.D. | 212-598-6412 | 55 | Children to age 18 |
| NY | Hospital for Special Surgery | Kathryn O. & Alan C. Greenberg Center for Skeletal Dysplasias | Cathleen Raggio, M.D. | 212-774-7332 | 60 | Children & Adults |
| NY | University of Rochester Medical | University Orthopaedics | James Sanders, M.D.-Children | 585 275-1395 | 32 | Children & Adults |

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| | Center | | David Weber, M.D.–Children Emily Carmody, M.D.–Adults | (children) 585-275-5321 (adults) | | |
| NC | Carolinas Medical Center | Children’s Specialty Center | Charles P. McKay, M.D. | 704-381-8802 | 50 | Children to age 21 |
| OH | Cincinnati Children’s Medical Center | Skeletal Dysplasia & Connective Tissue Clinic | Howard Saal, M.D. | 513-803-1376 or 513-636-0010 | 20 | Children & Adults |
| OH | Nationwide Children’s Hospital | Metabolic Bone Disease Clinic | John Mahan, M.D. | 614-722-4363 | 91 | Children & Adults |
| OR | Oregon Health and Science University | Bone and Mineral Clinic | Lindsey Nicol, M.D.-Children Robert F. Klein, M.D.-Adults | 503-494-1926 (children) 503-494-3273 (adults) | ~60 | Children & Adults |
| OR | Randall Children’s Hospital at Legacy Emanuel | Pediatric Genetics Program Pediatric Development & Rehabilitation | George Anadiotis, D.O. | 503-413-4156 | | Birth to adult |
| OR | Shriners Hospital for Children – Portland | Metabolic & Skeletal Dysplasia Clinics | Dennis Roy, M.D. | 503-221-3784 | 60 | Children to age 21 |
| PA | Children’s Hospital of Philadelphia (CHOP) | Connective Tissue Disorders Clinics | Paige Kaplan, M.D. | 215-590-3376 | 25 | Prenatal to age 18 |
| PA | Shriners Hospital for Children – Philadelphia | | Nancy Lord, RN | 215-430-4097 | | Birth to age 18 |
| SC | Shriners Hospital for Children – Greenville | General Orthopedic Clinic | Whitney Gibson DO | 864-240-3137 | 24 | Children to age 21 |
| TN | Monroe Carrel, Jr. Children’s Hospital at Vanderbilt | The Vanderbilt Program for Pediatric Metabolic Bone Disease | Jill H. Simmons, M.D. | 615-936-8866 | 60 | Children to age 19 |
| TN | Vanderbilt University Medical Center | Program for Adult Metabolic Bone Disease | Kathryn Dahir, M.D. | 615-343-8332 | 11 | Adults |
| TX | Baylor College of Medicine at Texas Children’s Hospital | Skeletal Dysplasia Clinic | Brendan Lee, M.D. | 832-822-4298 | 60 | Children & Adults |
| TX | Shriners Hospital for Children – Houston | Osteogenesis Imperfecta Clinic | Sandra Harper, NP | 713-793-3741 | ~80 | Children to age 18 |
| UT | Shriners Hospital for Children -- Intermountain | OI Multidisciplinary Clinic | Angela Bytheway, RN | 801-536-3777 Option # 2 | 50 | Children to age 18 |
| DC | Children’s National Medical Center | Bone Health Clinic | Laura L. Tosi M.D. | 202-476-3526 | 51 | |
| DC | Children’s National Medical Center | Skeletal Dysplasia Clinic/ - Department of Genetics | Kenneth N. Rosenbaum, M.D. and Dina J. Zand, M.D. | 202-476-2187 | “ | Genetic counseling for adults |
| DC | Children’s National Medical Center | Fetal Medicine Institute | Ask to speak to genetic counselors | 202-476-7409 | “ | Prenatal diagnosis |
| WA | Seattle Children’s Hospital | Skeletal Health Program- | Michael J Goldberg, M.D. & | 206-987-2109 | 25 | Children & Adults |

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| | | Metabolic Bone Disease Clinic | Ian Glass, M.D. | | | Diagnosis, Management, and Treatment |
| WA | Seattle Children's Hospital | Skeletal Health Program-Medical Genetics | Ian Glass, M.D. | 206-987-2056 | " | |
| WA | Shriners Hospital for Children – Spokane | | Paul Caskey, M.D. | 888-895-5951 | | Children to age 18 |
| WA | University of Washington Medical Center | Genetic Medicine Clinic | Peter H. Byers, M.D. | 206-598-4030 | 12 | Children & Adults |
| WI | University of Wisconsin | Metabolic Bone Disease Clinic | Robert D. Steiner, M.D. | 608-263-3301 | 10 | Children & Adults |
| Quebec, Canada | Shriners Hospital for Children – Canada | OI Clinic | Francis Glorieux, OC, M.D., PhD | 800-361-7256 X 8538 (in Canada) 514-282-8538 (from USA and elsewhere) | 150 | Children to age 21 |
| New South Wales, Australia | The Children's Hospital at Westmead | Connective Tissue Dysplasia Clinic | Professor Andreas Zankl | (+61-2) 9845-0000 | 123 | Children to age 18 with coordinated care for transition to adult services |

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