

An OI clinic offers people with OI the benefit of a medical team whose members are 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, in conjunction with the OI Clinic doctors.

This 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.

Key to Program Descriptions:

A = Coordinated Care B = Appointments with Individual Physicians
 C = Appointments with Inter-disciplinary Team members D = Research Protocols

Arizona

Children's Clinic for Rehabilitative Services (CCRS)

2600 N. Wyatt Dr.
 Tucson, AZ 85712
 Clinic Director: Sydney Rice, M.D.
 Clinic Hours: Monday–Friday 8-5
 Appointments & Information:
 Eileen Woods, LPN 520 324-3254 or
 Eileen.woods@tmcaz.com
 First call 520-324-5437 for application
 Services: Children to age 21
 OI patients seen last year: 29
 Treatment Programs: C

California

Cedars-Sinai Medical Center

Program Name: **Medical Genetics Clinic**
 8700 Beverly Blvd. Suite 665
 Los Angeles, California 90048
 Clinic Director: David Rimoin, M.D., Ph.D.
 Clinic Hours: Tuesday 8–1, Wednesday
 12:30–4
 Information: Tara Funari, MS CGC 310-423-
 4495 or tara.funari@cshs.org
 Appointments: Tami Kendra 310-423-9914
 Web Site: www.cedars-sinai.edu/medicalgenetics
 Services: Children & Adults
 OI patients seen in last year: 10
 Treatment Programs: A, B, C

Shriners Hospital for Children – Los Angeles

Program Name: **OI Clinic**
 3160 Geneva Street
 Los Angeles, California 90020
 Clinic Director: Gayle Tyerman, M.D.
 Clinic Hours: Monday 9-4:30
 Appointments: Faviola Ramirez 213-368-
 3366
 Information: Dr. Tyerman at
gytyerman@shrinenet.org
 Information & contact for families: Vivian
 Medrano, RN 213-368-3300
 Services: Infants & Children to age 18
 OI patients seen last year: 200
 Treatment Programs: A, C

UCLA School of Medicine

Program Name: **Pediatric Bone and Mineral Clinic**
 10833 LeConte Ave.
 Los Angeles, California 90095
 Clinic Directors: William Oppenheim, M.D. &
 Isidro Salusky, M.D.
 Clinic Hours: Monday 9-12
 Information, family contact, & appointments:
 Barbara Gales, RN 310-206-0799 or
bgales@mednet.ucla.edu
 Services: Children & Adults
 OI patients seen last year: 70
 Treatment Programs: B, D

Children's Hospital Central California

Program Name: **Medical Genetics/Metabolism**

9300 Valley Children's Place
Madera, California 93638
Clinic Director: Susan Winter, M.D.
Clinic Hours: Monday–Friday 8–5
Information: Sue Rosenthal, RN 559-353-6400

Appointments: 559-353-6400
Web Site: www.childrenscentralcal.org
Services: Children to age 18
OI patients seen last year: 28
Treatment Programs: A, C

Kaiser Permanente

Program Name: **Skeletal Dysplasia Clinic**
280 W. MacArthur Blvd.

Oakland, California 94611
Clinic Director: Katherine Dawson, M.D.
Clinic Hours: 3rd Friday mornings of the month (ex. Aug. & Dec.)
Information, family contact & appointments:
Ericka Okenfuss, MS, 916-614-5177 or
Ericka.okenfuss@kp.org
Web site: <http://genetics.kaiser.org>
Services: Children & Adults
OI patients seen last year: 9
Treatment Programs: A, B

Shriners Hospital for Children - Northern CA

2425 Stockton Blvd.
Sacramento, California 95817
Clinic Director: Jennette Boakes, M.D.
Clinic Hours: Monday–Friday 8–3
Information: Ary Arauz, PA, 916-453-2000 ext. 3100
Appointments: 916-453-2180
New Patients: apply for care through admissions office: 916-453-2000
Web Site: www.shrinershq.org
Services: Children to age 18 within general orthopedic program
OI patients seen last year: 42
Treatment Programs: B, D

Delaware

A.I. duPont Hospital for Children
Program Name: **Skeletal Dysplasia Program**

1600 Rockland Road
Wilmington, Delaware 19803
Clinic Directors: Richard Kruse, D.O. & Michael Bober, M.D., Ph.D.
Clinic Hours: Monday-Friday

(A.I. DuPont continued)
Appointments: 302-651-4200 (orthopedics) or 302-651-5916 (genetics)
Information: Lauren Davey 302-651-5916
Web Site: www.nemours.org
Services: Children to age 18
OI patients seen last year: 75
Treatment Programs: A, B, C, D

Florida

Shriners Hospital for Children - Tampa

12502 USF Pine Drive
Tampa, Florida 33612
Chief of Staff: Dennis P. Grogan, M.D.
Clinic Hours: Monday-Friday 8–5
Information: Lisa Green, RN
Care Coordinator 813-972-2250 ext. 7530
lgreen@shrinenet.org
Appointments: Applications Department 813-866-7740 or toll free 888-665-5437
Web Site: www.shrinershq.org
Services: Children to age 18 within general orthopedic program
OI patients seen last year: 99
Treatment Programs: A, B, C, D

Hawaii

Shriners Hospital for Children - Honolulu

1310 Punahou Street
Honolulu, Hawaii 96826
Clinic Director: Craig Ono, M.D.
Clinic Hours: Monday–Friday 8-4:30
Information: Celeste Olivares RN, BSN
Nurse Care Coordinator
Appointments: 888-888-6314 or 808-951-3620
Web Site: <http://www.shrinershq.org>
Services: Children to age 21 within general orthopedic program
OI patients seen last year: 30
Treatment Programs: A

Illinois

Shriners Hospital for Children – Chicago
Program Name: **Osteogenesis Imperfecta Clinic**

2211 N. Oak Park Ave.
Chicago, Illinois 60707-3392
Clinic Director: Peter Smith, M.D.
Clinic Hours: Monday, Tuesday, Friday
Information: Jen Joy Rhomberg 773-385-5579
Web Site: www.shrinershq.org
Services: Children to age 21
OI patients seen last year: 150
Treatment Programs: A, B, C, D

Indiana

Riley Hospital/ Indiana University

Program Name: **Bone Dysplasia Clinic**

975 West Walnut St. IB-130

Indianapolis, IN 46202

Clinic Director: Bryan Hainline, M.D.

Clinic hours: 3rd Wednesday of month

Appointments: Iris Pettigrew 317-278-1956

Services: Children & Adults

OI patients seen last year: 60

Treatment Programs: A, B, C, D

Kentucky

Shriners Hospital for Children - Lexington

1900 Richmond Road

Lexington, Kentucky 40502

Clinic Hours: Monday-Friday 9–4

Information: Rhonda Weiler, RN, BSN, Care
Coordinator

859-268-5740

Appointments: Pam Tuttle 859-266-2101

Web Site: www.shrinershq.org

Services: Children to age 21

OI patients seen last year: 30

Treatment Programs: B

Louisiana

Shriners Hospital for Children - Shreveport

3100 Samford Ave.

Shreveport, Louisiana 71103

Clinic Director: Richard McCall, M.D.

Clinic Hours: Monday-Thursday 8:30–3

Information: Cathy Taron, RN, Care

Coordinator 318-222-4296 or

ctaron@shrinenet.org

Appointments: Cathy sledge 800-830-0606

Web Site: www.shrinershq.org

Services: Children to age 21

OI patients seen last year: 35

Treatment Programs: A, B, C

Matrix DNA Diagnostics

Tulane University Health Sciences Center

1430 Tulane Ave., TB-28, Tidewater Room
2140

New Orleans, Louisiana 70112-2899

Laboratory Directors: Hans Andersson, M.D.
& Marilyn Li, M.D.

Hours: Monday-Friday 8– 5

Information & Appointments:

Charlene Crain, MBA, BSMT (ASCP),

Laboratory Supervisor

Telephone: 504-988-7706, Fax: 504-988-

7704 or ccrain@tulane.edu

(Matrix DNA continued)

Web Site:

www.som.tulane.edu/gene_therapy/matrix/matrix_dna_diagnostics.shtml

Services: Genomic Testing Only

Maryland

The Kennedy Krieger Institute

Program Name: **OI Program at the
Kennedy Krieger Institute**

707 N. Broadway

Baltimore, Maryland 21205

This program interacts with related Pediatric
& Adult services at Johns Hopkins Hospital

Clinic Directors: Jay Shapiro, M.D.

Assistant Director: Pending

Clinic Hours: Monday-Friday: App'ts

available throughout the week except

Thursday

Information: Sally Snader, RN, BSN, Clinic

Coordinator 443-923-2704

OI Research Nurse: Pamela Melvin, RN,

BSN 443-923-2707

New Appointments: 888-554-2080

Administrative Coordinator: Dionna Hicks

443-923-2703

Web Site: www.osteogenesisimperfecta.org

Services: Children & Adults; referrals to

Johns Hopkins Hospital

OI patients seen last year: 250

Treatment Programs: A, B, C, D

National Institutes of Health

OI Program

10 Center Drive

Bldg 10/Rm 10N260

Bethesda, Maryland 20892

Principal Investigator: Joan Marini, M.D.,
Ph.D.

Clinic Hours: Appointment Only

Appointments & Information: Cathy

Reisenberg, PhD, FNP-BC

301-496-0741 or oiprogram@mail.nih.gov

Web Site: www.oiprogram.nichd.nih.gov

Services: Children accepted into clinical trial
and adults being followed post clinical trial

OI patients seen last year: Over 60

Treatment Programs: A, B, C, D

Massachusetts

Children's Hospital Boston

Program Name: **OI Team**

300 Longwood Ave.

Boston, MA 02115

Clinic Director: Samantha A. Spencer, M.D.

Appointments: 617-355-6021

(Children's Hospital Boston continued)
Information: Dr. Spencer: 617-355-6808
Samantha.spencer@childrens.harvard.edu
Web Site: www.childrenshospital.org/ortho
Services: Orthopedic clinic: Children & Adults to age 35
Coordinates adult care at nearby hospital
Endocrine/Genetics: Children to age 21
OI patients seen last year: 100
Treatment Programs: A, B, C, D

Minnesota

Gillette Children's Specialty Healthcare

Program Name: **Orthopedic Clinic**

200 E. University Ave.

St. Paul, Minnesota 55101

Clinic Director: Stephen B. Sundberg, M.D.

Clinic Hours: Varies, depending on specialist

Appointments & Information:

Sue Murr or Paul Fiore, Acting Orthopaedic

Program Managers 651-229-1758 or

smurr@gillettechildrens.com

Services: Children to age 21

OI patients seen last year: 45

Treatment Programs: A, B, C

Shriners Hospital for Children - Twin Cities

Program Name: OI Clinic

2025 E. River Parkway

Minneapolis, Minnesota 55414

Clinic Director: Ken Guidera, M.D.

Clinic Hours: Monday-Friday 8:30-4

Information: Karen Boyer, 612-596-6105,

kboyer@shrinenet.org

Web Site: www.shrinershq.org

Services: Children to age 17

OI patients seen last year: Approx. 25

Treatment Programs: A, B, C

Missouri

Children's Mercy Hospital and Clinics

OI services through Children's Mercy

Kidney Center

2401 Gillham Rd.

Kansas City, Missouri 64108

Clinic Director: Tarak Srivastava, M.D.

Clinic Hours: Monday-Friday 8-4:30

Information: Patricia Swartz, RN, 816-234-

3312, or paswartz@cmh.edu

Appointments: 816-234-3030 or 800-276-

0985

Web Site: www.childrens-mercy.org

Services: Children to age 18

OI patients seen last year: 50

Treatment Programs: B

Shriners Hospital For Children – St. Louis

Program Name: **Research Clinic**

2001 South Lindbergh Blvd.

St. Louis, Missouri 63131

Clinic Director: Michael Whyte, M.D.

Clinic Hours: Tuesday & Thursday

Information: Karen Clements, RN, 314-432-

3600 ext.1637 or kclements@shrinenet.org

Appointments: Applications Department

314-432-3600 ext. 1119

Web Site: www.shrinershq.org

Services: Children to age 21

OI patients seen last year: 50

Treatment Programs: A, B, C, D

Barnes-Jewish Hospital

Division of Bone and Mineral Diseases

216 S. Kingshighway Blvd.

St. Louis, Missouri 63110

Dr. Michael Whyte, Clinic Director

Clinic Hours: Thursday

Appointments: 314-454-7775 Option #1

Services: Adults

Treatment Programs: B

University of Missouri – Columbia

Program Name: **Skeletal Dysplasia Clinic**

One Hospital Dr.

Columbia, MO 65212

Clinic Director: Daniel Hoernschemeyer, MD

Clinic Hours: Columbia: Mondays &

Thursdays

Jefferson City: Wednesday afternoons

Springfield: Every three months

Information & Appointments: Holly Wheatley

573-884-2522

Web Site: ww.ortho.muhealth.org/pediatrics

Services: Children to age 18

OI patients seen last year: 5

Treatment Programs: B

Nebraska

Children's Hospital & Medical Center

Program Name: **OI Clinic**

8200 Dodge St.

Omaha, NE 68114-4113

Clinic Medical Director: Richard Lutz, M.D.

Clinic Hours: One day a month 9– 5

Information & contact for families: Holly

Wulf, RN 402- 955-4157

Appointments: 402- 955-4199

Services: Children

OI patients seen last year: 65 Children

Treatment Programs: A, C, D

New York

Hospital for Joint Diseases Pediatric Initiative for Bone Health

301 East 17th St. Rm. 204
New York, NY 10003
Clinic Director: Patricia Poitevien, M.D.
Clinic Hours: Monday 9am-12pm,
Wednesday 9am-3pm & Thursday 1pm-3pm
Information & Appointments: 212-598-6412
Web Site: www.nyuhjdcenterforchildren.org
Services: Children to age 18
OI patients seen last year: 55
Treatment Programs: A

Hospital for Special Surgery Center for Skeletal Dysplasias and OI Clinic

535 E. 70th St.
New York, NY 10021
Program Names:
1) **OI Clinic**
2) **Kathryn O. and Alan C. Greenberg
Center for Skeletal Dysplasias (CSD)**
Directors OI Clinic: Daniel Green, M.D. &
Cathleen Raggio, M.D.
Directors CSD: Jessica G. Davis, M.D. &
Cathleen Raggio, M.D.
Clinic Hours: OI Clinic: 2nd and 3rd Monday
of each month
CSD: 2nd or 3rd Monday mornings each
month
Information and appointments:
OI Clinic: Mary Phelan, RN 212-774-1365 or
Dr. Green 212-606-1631
CSD: Erin M. Carter 212-774-7332 or Dr.
Raggio 212- 606-1339 or CSD@Hss.edu
Web site: www.hss.edu/skeletal-dysplasias.asp
Services: Children & Adults
OI patients seen last year: 60
Treatment Programs: A, B, C, D

University of Rochester Medical Center Program Name: University Orthopaedics

601 Elmwood Ave.
Rochester NY 14642
Clinic Directors:
James Sanders, M.D. Children
Susan Bukata, M.D. - Adults
Clinic Hours: Monday-Friday 8-4:30
Appointments: 585-275-5321
Web Site: www.urmc.rochester.edu
Information:
Services: Children & Adults
OI patients seen last year: 35
Treatment Programs: A, B, C

North Carolina

Carolinas Medical Center Program Name: Children's Specialty Center

1000 Blythe Blvd.
P.O. Box 32861
Charlotte, NC 28232-2861
Clinic Director: Charles P. McKay, M.D.
Clinic Hours: Monday 1-5, Tuesday 1-5,
Thursday 8-12, Friday 8-12
Appointments: Diane Whitfield: 704-381-
8800
Web Site: www.levinechildrenshospital.org
Services: Children to age 21
OI patients seen last year: 38
Treatment Programs: A, B

Ohio

Cincinnati Children's Hospital Medical Center

Program Name: **Skeletal Dysplasia &
Connective Tissue Clinic**
3333 Burnet Ave., ML 4006
Cincinnati, Ohio 45229
Clinic Director: Brad T. Tinkle, M.D., Ph.D.
Clinic Hours:
Skeletal Dysplasia Clinic – fourth Thursday
each month and as needed
Information: Carrie Atzinger, MS, CGC, 513-
803-2663
Appointments: Scheduling 513-636-4760,
ext. 1
Web Site: www.cincinnatichildrens.org
Services: Children & Adults
OI patients seen last year: 20
Treatment Programs: A, B, C, D

Nationwide Children's Hospital Metabolic Bone Disease Clinic

700 Children's Dr.
Columbus, OH 43205
Clinic Director: John D. Mahan, M.D.
Clinic Hours: Tuesday 8-1
Appointments: 614-722-4363
Information: Marney Davis, RN, BSN or Beth
Kossmann, RN 614-722-4363
Web site:
www.nationwidechildrens.org/nephrology
Services: Children & Adults
OI patients seen last year: 75
Treatment Programs: A, B, C, D

Oregon

Oregon Health & Science University Bone and Mineral Clinic

3181 S.W. Sam Jackson Park Road, Mail
Code: CR113

Portland, OR 97239-3098

Clinic Director: Robert F. Klein, M.D.

Information & contact for families:

Sandra L. Veith, Research Associate 503-
494-5630

Services: Adults

OI patients seen last year: 60+

Treatment Programs: A, B, C, D

Shriners Hospital for Children – Portland

3101 SW Sam Jackson Park Rd.

Portland, OR 97239

Program Name: **Metabolic & Skeletal**

Dysplasia Clinics

Clinic Director: Robert Steiner, M.D.

Clinic Hours: 1st Tuesday of month for

Metabolic Clinic; 3rd Friday Skeletal

Dysplasia Clinic 8:30-12:00

Information: Vonda Vensel, RN, 503-221-
3784

Appointments: Barb Flaherty, 503-221-3480

New Patient Coordinator

Web Site: www.shrinershq.org

Services: Children to age 21

OI patients seen last year: 60

Treatment Programs: A, B, C, D

Legacy Children's Hospital

Program Name: **Pediatric Development &
Rehabilitation**

2801 N. Gantenbein

Portland, OR 97227

Clinic Director: George Anadiotis, M.D.

Clinic Hours: Monday-Friday 9-5

To make an appointment: 503-413-4505

Services: Birth to Adult

OI patients seen last year: unknown

Treatment Programs: A, B

Pennsylvania

Children's Hospital of Philadelphia (CHOP)

Program Name: **Connective Tissue
Disorder Clinic**

34th St. and Civic Center Boulevard

Philadelphia, PA 19104

Clinic Directors: Paige Kaplan, M.D.

Physician: Michael Levine, M.D.

Clinic Hours: CHOP-Children: Wed. 1-5

Information & Contact for Families: Kristi

Koch Fitzgerald, MS, CGC

(CHOP continued)

or Curtis R. Coughlin II, MS, CGC

Telephone & Email: 215-590-3376,

fitzgeraldk@email.chop.edu or

coughlincu@email.chop.edu

Appointments: Daria Tolentino 215-590-
3376

Services: Children

OI patients seen last year: 25

Treatment Programs: A, C

Hospital of the University of Pennsylvania (HUP) – University of Pennsylvania Health Services

Program Name: **Connective Tissue**

Disorder Clinic

3400 Spruce St.

Philadelphia, PA 19104

Clinic Director: Reed Pyeritz, M.D.

Clinic Hours: HUP – Adults: Monday 12-4,

Thursday 8:30-4

Information & Contact for Families: Barbara

Bernhardt, MS, CGC

Telephone & Email: 215-662-4740,

Barbara.bernhardt@uphs.upenn.edu

Appointments: Georgia Griffin 215-662-4740

Services: Adults

OI patients seen last year: 12

Treatment Programs: A, C

Shriners Hospital for Children – Philadelphia

3551 North Broad St.

Philadelphia, PA 19140

Clinic Hours: Wednesday 8-4, Friday 8-12
(Upper extremities)

Wednesday, Thursday & Friday 8-4 (Lower
extremities)

Appointments: Scheduling Secretary 800-
281-4050 ext. 4073

Web Site: www.shrinershq.org

Services: Birth to age 18

OI patients seen last year:

Treatment Programs: A, B, C

Shriners Hospital for Children – Erie

1645 West 8th St.

Erie, PA 16505

Clinic Director: William Schrantz, M.D.

Clinic Hours: Monday-Friday

Information: Janet Noland, MPT or

jnoland@shrinenet.org

Appointments: 800-873-5437

Services: Birth to age 21

OI patients seen last year: 30

Treatment Programs: A, B, C, D

South Carolina

Shriners Hospital for Children – Greenville

Program Name: **General Orthopedic Clinic**
950 West Faris Road
Greenville, South Carolina 29605
Clinic Director: Pete Stasikelis, M.D.
Clinic Hours: Monday-Friday 7–5
Information: Kellie Mason, RN, BSN, Clinical Coordinator Outpatient Dept.
Appointments: 864-240-3137
Services: Children to age 18
OI patients sent last year: 22
Treatment Programs: A

Texas

Baylor College of Medicine at Texas Children's Hospital

Program Name: **Skeletal Dysplasia Clinic**
6701 Fannin St. CC-1510
Houston, Texas 77030-2399
Clinic Director: Brendan Lee, M.D., Ph.D.
Clinic Hours: 2nd Friday of month 1:30–5:00
Appointments, Information & Family contact Marie Prescott 832-822-4298
Web Site: www.texaschildrenshospital.org
Services: Children & Adults
OI Patients seen last year: 28
Treatment Programs: A, B, D

Shriners Hospital for Children – Houston

Program Name: **OI Clinic**
6977 Main Street
Houston, Texas 77030-3701
Clinic Director: Lynnette Mazur, M.D.
Clinic Hours: 4th Thursday every other month 1:00-4:30
Information: Jenice Haines, RN, MSN 713-797-1616
New Applications: Aura Arand, Applications Secretary 713-797-1616 Ext. 3765
Services: Children to age 17
OI patients seen last year: unknown
Treatment Programs: A, C

Utah

Shriners Hospital for Children – Intermountain

Program Name: **OI Multidisciplinary Clinic**
Fairfax Road at Virginia St.
Salt Lake City, Utah 84103
Clinic Hours: January, April, July, October 2nd Wednesday 8–12
Information: Angela Bytheway, RN, 801-536-3565
Appointments: Applications: 800-841-0204

(Shriners Salt Lake City continued)

Web Site: www.shrineshq.org
Services: Children to age 18
OI patients seen last year: 50
Treatment Programs: A, B, C

Washington

Seattle Children's Hospital Medical Genetics Clinic & Skeletal Health Program

Box 359300 (CH-47)
Seattle, Washington 98105
Genetics Clinic Director: Ian Glass, M.D.
Skeletal Health Director: Michael Goldberg, M.D.
Medical Genetics Clinic Hours: Tuesday 8– 5
Skeletal Health Clinic Hours: Monday 8-5, Tuesday 8-12, Wednesday 1-5
Appointments: 206-987-2056 (Genetics) or 206-987-2109 (Skeletal Health)
Services: Children & Adults
OI Patients seen last year: 15
Treatment Programs: A, B, C

University of Washington Medical Center

Program Name: **Medical Genetics Clinic**
Box 357720
Seattle, Washington 98195-7720
Clinic Director: Peter Byers, M.D.
Clinic Hours: Tuesday 8–2
Appointments: 206-598-4030
Services: Children & Adults
OI Patients seen last year: 8
Treatment Programs: A, B, C

Shriners Hospital for Children - Spokane

911 W. 5th Ave.
Spokane, Washington 99204
Chief of Staff: Paul Caskey, M.D.
Clinic Hours: Monday-Thursday
Information: Dr. Caskey, pcaskey@shrinenet.org
Appointments: 888-895-5951
Web Site: www.shrinershq.org
Services: Children to age 21
(Shriners Spokane WA continued)
OI patients seen last year: 25
Treatment Programs: A, B, C, D

Washington, D.C.

Children's National Medical Center Skeletal Dysplasia Clinic/Department of Genetics

111 Michigan Ave., NW
Washington, DC 20010

(Children's National Med. Ctr. Continued)
Clinic Director: Kenneth N. Rosenbaum, MD
Clinic Hours: Genetics Department
2nd Tuesday of the month 8:30-12:30
Appointments and Skeletal Dysplasia Clinic
information:
Deborah Copenheaver, MS 202-476-4167
Fracture care through Orthopedics Dept.,
Laura Tosi, M.D. 202-476-5562
Orthopedic information and contact for
families Nancy Harry, LICSW at
nharry@cnmc.org
Web Site: www.dcchildrens.org (go to
genetics)
Services: Children to Adults
Genetic counseling is open to adults
OI patients seen last year: 40
Treatment Programs: A, B, C

Wisconsin

Midwest Regional Bone Dysplasia Clinic University of Wisconsin

1500 Highland Avenue
Madison, Wisconsin 53705
Clinic Director: Richard Pauli, M.D., Ph.D.
Service Provider: Phil Giampietro, M.D.
Clinic Hours: Wednesday 8:30- 4:30
Information & Appointments:
Sue Kalscheur, PA, Clinic Coordinator 608-
262-2507 or
skalscheur@waisman.wisc.edu
Services: Children & Adults
OI patients seen last year: 7
Treatment Programs: A, B

Canada

Shriners Hospital for Children – Canada

Program Name: **OI Clinic**
1529 Cedar Ave.
Montreal, Quebec
Canada H3G 1A6
Clinic Director: Francis Glorieux, M.D., Ph.D.
Information, Contact for Families &
Appointments:
Helene Gauthier 800-361-7256 ext. 6999 (in
Canada)
514-282-6999 (from USA and elsewhere) or
hgauthier@shrinenet.org
Web Site: www.shriners-genetics.mcgill.ca
Services: Children to age 21
OI patients seen last year: 150
Treatment Programs: A, B, C, D

The Hospital for Sick Children Skeletal Dysplasia Clinic-Genetics

555 University Ave.
Division of Clinical & Metabolic Genetics
Toronto, Ontario, M5G 1X8 Canada
Director: Roberto Mendoza-Londono, MD
Clinic Hours: Once a week
To make an appointment: Lucie Dupuis,
MSc 416-813-6387
Services: Children to age 21; Adults
evaluated and referred elsewhere
OI patients seen last year: 15
Treatment Programs: A, C

United Kingdom

Sheffield Children's NHS Trust Metabolic Bone Disease Team

Western Bank, Sheffield
S10 2TH, UK
Clinic/Team Director: Prof. Nicholas J.
Bishop
Clinic Hours: Clinic: Tuesday 9-12:30
Inpatient therapy: Monday-Friday
Information & Contact for Families:
Elaine Walker, Clinical Nurse Specialist
(+44) 01142267890 or
Elaine.walker@sch.nhs.uk
Appointments: Medical Practitioner referral
only
Web Site: www.sheffieldchildrens.nhs.uk
Services: Children to age 21
OI patients seen last year: 265
Treatment Programs: A, B, C, D

Australia

The Children's Hospital at Westmead Program Name: **Connective Tissue Dysplasia Clinic (CTDC)**

Corner Hawkesbury Road & Hainsworth St.
Westmead NSW 2145
Postal Address: Locked Bag 4001,
Westmead NSW 2145
Clinic Director: Professor David Sillence
Clinic Hours: Tuesday 9:30-1:30
Information: Ms. Cheryl Cotton
(+61-2) 9845-0000 or
CheryC3@chw.edu.au
Web Site: www.chw.edu.au
Services: Children to age 18
coordinated care for transition to adult
services
OI patients seen last year: 112
Treatment Programs: A, B, C, D

Services for Adults

All of the programs listed in this directory see children who have OI. The following centers also see adults with OI. See the state-by-state list for complete contact information. The range of services offered differs a great deal from place to place. Contact the clinic directly, or the OI Foundation National Resource Center for details.

California

Cedars-Sinai Medical Center
UCLA School of Medicine
Kaiser Permanente

Indiana

Riley Hospital/Indiana University

Maryland

The Kennedy Krieger Institute

Missouri

Barnes-Jewish Hospital

New York

Hospital for Special Surgery
University of Rochester

Ohio

Cincinnati Children's Hospital Medical Ctr
Nationwide Children's Hospital

Oregon

Oregon Health Science University
Legacy Children's Hospital

Pennsylvania

Hospital of the University of Pennsylvania

Texas

Baylor College of Medicine

Washington

Children's Hospital & Regional Medical
Center
University of Washington Medical Center

Washington, D.C.

Children's National Medical Center

Wisconsin

Midwest Regional Bone Dysplasia Clinic

Linked Clinical Research Centers

The OI Foundation has begun development of a group of Linked Clinical Research Centers (LCRC). The goal of these centers is to provide quality care, and conduct research that expands our understanding of this complex disorder and improves treatments.

Following are the first six sites:

Shriners Hospital – Chicago, IL
Kennedy Krieger Institute – Baltimore, MD
National Institutes of Health – Bethesda, MD
Oregon Health & Science University/Portland Shriners Hospital – Portland, OR
Baylor Medical Center/Texas Children's Hospital – Houston, TX
Shriners Hospital – Montreal Canada