Editors’ note and disclaimer: The resource list provided in this guide is not comprehensive. Inclusion on the list does not imply endorsement by the Fanconi Anemia Research Fund, Inc. Families are encouraged to ask clinicians about their experience treating patients with Fanconi anemia.

U.S. Fanconi Anemia Treatment Resource Guide

**Children’s Hospital Central California**
Department of Pediatric Hematology SC-62
9300 Valley Children’s Place
Madera, CA 93636 -8762
Telephone: 559-353-5460  Fax: 559-353-5095
Email: vbalasa@childrenscentralcal.org

- Laura Andrews, RN, Transplant Coordinator
- Vinod Balasa, MD, Director of Hematology/Oncology
- Kelly Folmer, RN, CPNP
- Terea Giannetta, DNP, CPNP, Nurse Practitioner
- Catherine Hanson, LCSW
- Nancy G. Hatcher, MSW, Clinical Social Worker
- Mary Beth Jones, Child Life Coordinator
- William Koole, Pharm.D
- Shari Langer, PhD, Clinical Psychologist
- J. Daniel Ozeran, MD, PhD
- Latha Rao, MD
- Faisal Razzaqi, MD
- Ruth Rolen-Martinez, RN, BSN, Clinical Coordinator
- Wendy Tcheng, MD
- Ruetima Titaphiwatanakun, MD
- Pamela Young, RD

**Services Offered:**
Children’s Hospital Central California provides diagnostic, treatment and referral services to children ages birth to 21 years in California’s Central Valley, at the only pediatric hospital between Los Angeles and San Francisco and the largest children’s hospital between San Diego and San Francisco. Patients are seen and treated from initial diagnosis to and beyond bone marrow transplant for which patients are referred to nationally recognized transplant centers. Patients receive specialty care within the Fanconi anemia treatment program as well as from Genetics, Orthopaedics, Cardiology, Behavioral Health Sciences and other specialty services. Patients with Fanconi anemia are provided supportive, educational, and consultive services to further enhance care.

**Children’s Hospital Los Angeles, Keck School of Medicine, University of Southern California**
4650 Sunset Boulevard, MS #62
Los Angeles, CA 90027

- Neena Kapoor, MD, Division of Research Immunology & Bone Marrow Transplant
Telephone: 323-361-2546  Fax: 323-361-8068
Email: nkapoor@chla.usc.edu

**Children’s Hospital of Wisconsin**
MACC Fund Research Center, Suite 3018
8701 Watertown Plank Road
Milwaukee, WI 53226

Monica Thakar, MD
Telephone: 414-955-4170  Fax: 414-955-6543
Email: mthakar@mcw.edu

**Services Offered:**

- Evaluation of new and previously diagnosed patients;
- Personalized treatment regimens and coordination of care by specialists in hematology, bone marrow transplantation, cardiology, endocrinology, genetics, gastroenterology, nephrology, urology, orthopedics, social work;
- Stem cell collection, storage, and infusion;
- Expertise in matched sibling donor, unrelated donor, and haploidentical (alternative donor) transplantation for Fanconi anemia;
- Collaborations with Fred Hutchinson Cancer Research Center and Memorial Sloan-Kettering Cancer Center in alternative donor clinical trials.

**Note:** FANCD2 immunoblot=FANCD2 western=FANCD2 ubiquitination.
BONE MARROW FAILURE

Cincinnati Children’s Hospital Medical Center
Fanconi Anemia Comprehensive Care Center
MLC 11013
3333 Burnet Avenue
Cincinnati, OH 45229
www.cincinnatichildrens.org

- Erica L. Goodridge, RN, BSN, CPN, Care Manager, Fanconi Anemia Comprehensive Care Center
  Telephone: 513-636-3218  Fax: 513-636-7951
  Email: erica.goodridge@cchmc.org

- Stella Davies, MBBS, PhD, MRCP, Director, Bone Marrow Transplantation and Immune Deficiency
  Jacob G. Schmidlapp Endowed Chair
  Professor, UC Department of Pediatrics
  Telephone: 513-636-2469  Fax: 513-636-3549
  Email: stella.davies@cchmc.org

- Richard Harris, MD, Professor of Clinical Pediatrics
  University of Cincinnati College of Medicine
  Division of Blood and Marrow Transplantation and Immune Deficiency
  Cancer and Blood Diseases Institute
  Telephone: 513-803-9063  Fax: 513-636-7951
  Email: richard.harris@cchmc.org

- Lesley Breech, MD, Division Director, Pediatric and Adolescent Gynecology
  Associate Professor, UC Department of Surgery
  University of Cincinnati Department of Obstetrics and Gynecology
  Telephone: 513-636-2960  Fax: 513-636-8844
  Email: lesley.breech@cchmc.org

- Roger Cornwall, MD, Associate Professor of Pediatrics, Division of Orthopaedics (Hand Surgery)
  Telephone: 513-803-HAND  Fax: 513-636-3928
  Email: roger.cornwall@cchmc.org

- Jens Goebel, MD, Professor, Nephrology
  Telephone: 513-636-0993
  Email: jens.goebel@cchmc.org

- Sara C. Knapke, MD, Clinical Manager and Certified Genetic Counselor
  Telephone: 513-803-0211
  Email: sara.knapke@cchmc.org

- Samuel Kocoshis, MD, Professor
  Telephone: 513-636-4415
  Email: samuel.kocoshis@cchmc.org

- Sarah Lawson, MD, Assistant Professor, Endocrine
  Telephone: 513-736-4465
  Email: sarah.lawson@cchmc.org

- Nancy Doan Leslie, MD, Director, Biochemical Genetics Laboratory
  Director, ABMG-Accredited Clinical Training Program
  Professor, UC Department of Pediatrics
  Telephone: 513-803-2438  Fax: 513-636-7297
  Email: nancy.leslie@cchmc.org

- Charles T. Mehmman, MD, Director, Musculoskeletal Outcomes Research
  Co-Director, Brachial Plexus Center
  Professor, Division of Pediatric Surgery
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  Professor, UC Department of Pediatrics
  Telephone: 513-636-4975
  Email: kasiani.myers@cchmc.org

- Kasiani Myers, MD, Assistant Professor, U.S. Department of Pediatrics
  Telephone: 513-636-7287
  Email: kasiani.myers@cchmc.org

- Susan R. Rose, MD, MEd, Professor, UC Department of Pediatrics, Endocrine
  Telephone: 513-636-4744
  Email: susan.rose@cchmc.org

- Michael Rutter, MD, Pediatric Otolaryngologist and Director of Clinical Research
  Professor, UC Department of Pediatrics
  Otolaryngology - Head and Neck Surgery
  Telephone: 513-636-4881  Fax: 513-636-8133
  Email: mike.rutter@cchmc.org

- Thomas Ryan, MD, Assistant Professor, Cardiology
  Telephone: 513-636-9282
  Email: thomas.ryan@cchmc.org

- Mary Sutton, MD, Assistant Professor, UC Department of Pediatrics
  Telephone: 513-636-4222
BONE MARROW FAILURE

Robert E. Wood, MD. PhD. Director, Pulmonary Bronchoscopy Department
Professor, UC Department of Pediatrics
Telephone: 513-636-2776  Fax: 513-636-3845
Email: rewood@chmc.org

Services Offered:
- Evaluation of new and previously diagnosed patients;
- Personalized treatment regimens by specialists in bone marrow transplantation, cardiology, endocrinology, genetics, hematology, nephrology, urology, orthopedics, hand surgery, social work, and family support network;
- Pharmacological and other clinical trials (e.g., cytokines and flavonoids);
- Fanconi anemia repository for samples and data;
- Expertise in matched sibling donor and unrelated donor transplantation for Fanconi anemia;
- Fanconi anemia complementation and mutation analysis;
- Stem cell collection, storage, and reinfusion;
- Collaboration with, International Fanconi Anemia Registry (Arleen Auerbach, PhD).

City Of Hope
1500 E. Duarte Road
Duarte, CA 91010
Telephone: 626-301-8442

- Joseph Rosenthal, MD, Chair, Department of Pediatrics, Pediatric Hematology/Hematopoietic Cell Transplantation
  Email: jrosenthal@coh.org

- Anna Pawlowska, MD, Director, Pediatric Hematology/Hematopoietic Cell Transplantation
  Email: apawlowska@coh.org

- Nicole Karras, MD, Staff Physician, Pediatric Hematology/Hematopoietic Cell Transplantation
  Email: nkarras@coh.org

- Saro Armenian, MD. MPH, Associate Professor, Pediatric Hematology/Oncology and Population Sciences, Division of Outcomes Research
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- Julie Wolfson, MD, Staff Physician, Pediatrics; Assistant Professor, Population Sciences & Pediatrics
  Email: jwolfson@coh.org

- Debbie Hitt, RN, BSN, CPNPN, Nurse-Coordinator, Pediatric Hematology/Hematopoietic Cell Transplantation
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- Lisa Gutierrez, RN, MSN, CPNP, CPHON, Nurse Practitioner, Pediatrics
  Email: lisagutierrez@coh.org

- Nadia Ewing, MD, Director, Pediatric Hematology
  Email: newing@coh.org

- Lisa Pullens, RN, BSN, Nurse Coordinator, Pediatric Hematology
  Email: lpullens@coh.org

- Joyce Collins, PhD, Director, Cytogenetics
  Email: jcollins@coh.org

- Christina Cabanillas, LCSW, Social Worker, Pediatric Hematology/Hematopoietic Cell Transplantation
  Email: ccabanillas@coh.org

- Renee Ortiz, LCSW, Social Worker, Pediatric Hematology/Hematopoietic Cell Transplantation
  Email: roeortiz@coh.org

- April Sorrell, MD, Pediatric Hematology/Hematopoietic Cell Transplantation and Pediatric Clinical Cancer Genetics

- Smita Bhatia, MD, Pediatrics, Hematology/Hematopoietic Cell Transplantation and Director, Population Sciences

Cohen Children’s Medical Center of New York, Bone Marrow Failure Program
Division of Hematology/Oncology and Stem Cell Transplantation
269-01 76th Avenue, Rm. 255
New Hyde Park, NY 11040

- Adrianna Vlachos, MD, Assistant Professor of Pediatrics
  Head, Bone Marrow Failure Program and Associate Head, Stem Cell Transplant Program
  Telephone: 718-470-3611  Fax: 718-343-2961
  Email: avlachos@lij.edu
BONE MARROW FAILURE

- **Johnson M. Liu, MD.** Les Nelkin Professor of Pediatrics
  Head, Section of Experimental Hematology and Les
  Nelkin Memorial Pediatric Oncology Research
  Laboratory
  Telephone: 718-470-7174
  Email: jliu3@nshs.edu

- **Jeffrey M. Lipton, MD, PhD.** Professor of Pediatrics
  Chief, Division of Hematology/Oncology and Stem Cell
  Transplantation
  Telephone: 718-470-3460
  Email: jlipton@lij.edu

- **Nancy Barbach, LCSW,** Social Worker, Hematology
  Oncology and Stem Cell Transplantation
  Telephone: 718-470-3286
  Email: nbarbach@nshs.edu

Services Offered:
- Bone Marrow Failure Clinic offering comprehensive
  evaluation of adult and pediatric FA patients by an
  experienced team of multi-disciplinary specialists directed
  by medical and pediatric hematologists;
- Hematopoietic Stem Cell Transplant Program offering
  expertise in transplantation in bone marrow failure
  syndromes;
- Experimental Hematology Program studying molecular
  mechanisms of hematopoietic failure and oncogenesis in
  FA and other bone marrow failure syndromes.

Fanconi Anemia and Bone Marrow Failure
Multi-disciplinary Clinic at the Dana-
Farber/Boston Children’s Cancer and Blood
Disorders Center
Dana-Farber Cancer Institute
450 Brookline Avenue
Boston, MA 02215

- **Eva C. Guinan, MD,** Associate Professor of Radiation
  Oncology
  Director, Translational Research BWH/DFCI Department
  of Radiation Oncology
  Telephone: 617-632-4932 Fax: 617-632-3770
  Email: Eva_Guinan@dfci.harvard.edu

- **Lisa L. Brennan, BSN, RN,** Research Nurse
  Email: Lisa_brennan@dfci.harvard.edu

Services Offered:
- Comprehensive evaluation;
- Second opinions;
- Pre- and post-transplantation evaluation;
- Follow-up care and planning.

Boston Children’s Hospital
300 Longwood Avenue
Boston, MA 02115
http://www.childrenshospital.org/fa-bmf

- **David A. Williams, MD**
  Telephone: 617-919-2697
  Email: dawilliams@childrens.harvard.edu

- **Colin Sieff, MB BCh**
  Telephone: 617-355-2367
  Email: colin.sieff@childrens.harvard.edu

- **Mary Cogan, CPNP, RN, CPHON**
  Telephone: 617-355-8246 Fax: 617-730-0641
  Email: mary.cogan@childrens.harvard.edu

Dana-Farber Cancer Institute
450 Brookline Avenue
Boston, MA 02215
http://research.dfci.harvard.edu/dandrealab

- **Alan D’Andrea, MD**
  Telephone: 617-632-2080
  Email: alan_dandrea@dfci.harvard.edu

- **Lisa A. Moreau, MS, CLSpCG**
  Telephone: 617-632-6302
  Email: lisa_moreau@dfci.harvard.edu

Specialists:
Adolescent Medicine/Gynecology: Amy DiVasta, MD
Blood and Marrow (Stem Cell) Transplantation: Leslie
Lehmann, MD
Cardiology: David Harrild, MD, PhD
Endocrinology: Laurie Cohen, MD
Gastroenterology: Leonel A. Rodriguez, MD, MS
Genetics: Jonathan Picker, MD, PhD; Pam Hawley, MS, CGC
Hand Surgery: Brian Labow, MD
Hematology: David A. Williams, MD; Colin Sieff, MB
BCh; Mary Cogan, CPNP, RN, CPHON
Molecular Diagnostics: Alan D’Andrea, MD; Lisa
Moreau, MS, CLSpCG; Bai-Lin Wu, PhD, M Med
FACMG, Ann E. Reinhard, MS, CGC
Nephrology: Michael Ferguson, MD
Otolaryngology: Reza Rahbar, DMD, MD, FACS
Pulmonary Medicine/Aero-Digestive Disorders: Catherine
Sheils, MD
Social Work: Susanna Locke, LCSW
Urology: Hiep (Bob) Nguyen, MD

Services Offered:
- Our Nurse Practitioner arranges a comprehensive
evaluation for each new patient, including confirmation of diagnosis, genetic typing, HLA typing, and a multi-system evaluation. The team carefully examines previous diagnostic test results and past medical history to guide the initial evaluation in the multi-disciplinary clinic. This results in a written summary and recommendations for the referring physician and the patient’s family. Ongoing care may continue at Children’s or in partnership with the referring physician. Psychosocial support is available and an important part of our long-term care of families of patients with serious diseases.

- A variety of innovative clinical trials are available for enrollment. Two current studies for patients with Fanconi anemia are: 1) the use of danazol, an androgen and 2) a hematopoietic cell transplantation trial for those lacking a genotypically identical donor.
- Diagnosis of new FA patients through Clinical Laboratory Improvement Act (CLIA)-certified diepoxybutane (DEB) test.
- Complementation analysis via retrovirus gene transfer.
- Fundamental research in DNA repair pathways, induced pluripotent stem cells and gene therapy.
- Referral for pre-implantation genetic diagnosis services at two sites in Boston if we find disease-causing mutations.

Fred Hutchinson Cancer Research Center
1100 Fairview Ave N
Seattle, WA 98101
Telephone: 206-667-5000
www.fhcrc.org

Seattle Children’s Hospital
4800 Sand Point Way NE
Seattle, WA 98105
www.seattlechildrens.org

- Akiko Shimamura, MD, PhD, Director, Comprehensive Marrow Failure/MDS Program, Pediatric Hematology-Oncology, Seattle Children’s Hospital
Member, Fred Hutchinson Cancer Research Center
Professor of Pediatrics, University of Washington School of Medicine
Telephone: 206-987-2106 Fax: 206-987-3946
Email: ashimamu@fredhutch.org

- Hans-Peter Kiem, MD, Member, Fred Hutchinson Cancer Research Center
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- K. Scott Baker, MD, MS, Member and Director, Pediatric Blood and Marrow Transplantation and Survivorship Programs, Fred Hutchinson Cancer Research Center and Seattle Children’s Hospital
Professor of Pediatrics, University of Washington School of Medicine
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- Ann Woolfrey, MD, Director, Unrelated Donor Program Member, Fred Hutchinson Cancer Research Center, Pediatric Blood and Marrow Transplant Program
Professor of Pediatrics, University of Washington School of Medicine
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Email: awoolfre@fredhutch.org

- Jennifer Adair, PhD, Clinical Research Associate
Fred Hutchinson Cancer Research Center
Telephone: 206-667-7110 Fax: 206-667-6124
Email: jadair@fredhutch.org

- Pam Becker, MD, PhD. Associate Professor of Medicine, University of Washington School of Medicine, Department of Hematology
Telephone: 206-288-2294 Fax: 206-543-3560

Services Offered:
- Comprehensive Fanconi Anemia Program including evaluation and management of new and previously diagnosed pediatric and adult patients with FA;
- Personalized treatment regimens by specialists in hematology, bone marrow transplantation, cardiology, endocrinology, genetics, gastroenterology, nephrology, urology, orthopedics, and social work;
- Gene therapy trial; Fanconi anemia repository for samples and data;
- Stem cell collection, storage, and reinfusion;
- Expertise in matched sibling donor, unrelated donor, and haploidentical (alternative donor) transplantation for Fanconi anemia;
- Collaboration with Hospital de Clinicas, University of Parana, Brazil (Carmem Bonfim, MD and Ricardo Pasquini, MD, PhD).
Services Offered:
- Diagnosis and genetic counseling;
- Comprehensive medical treatment including gynecology and ENT specialists;
- Matched sibling and unrelated donor transplants.

International Fanconi Anemia Registry (IFAR)
The Rockefeller University
Part of New York Consortium for Inborn Errors of Hematopoiesis and Immunity (see also, Memorial Sloan Kettering Cancer Center, New York Presbyterian Hospital, and Hospital for Special Surgery)
Laboratory of Genome Maintenance
1230 York Avenue, Box 182
New York, NY 10065
http://lab.rockefeller.edu/smogorzewska/ifar/
Facebook: Fanconi Anemia Registry or Agata Smogorzewska

- Agata Smogorzewska, MD, PhD, Principal Investigator
  Telephone: 212-327-7850, or 8862 Fax: 212-327-8262
  Email: asmogorzewska@rockefeller.edu
  http://lab.rockefeller.edu/smogorzewska

- Arleen D. Auerbach, PhD, Co-Investigator
  Telephone: 212-327-7533, or 8862 Fax: 212-327-8262
  Email: auerbach@rockefeller.edu

- Jennifer Kennedy, MS, CGC, Genetic Counselor/Study Coordinator
  Telephone: 212-327-8612, or 8862 Fax: 212-327-8262
  Email: jkennedy@rockefeller.edu

Genetic Services on Research Protocol:
- International Fanconi Anemia Registry (IFAR);
- Mutation screening of probands (gene specific sequencing, next generation sequencing, whole exome sequencing, SNP analysis, and/or CHG) for genes under investigation by the laboratory;
- Genomic analysis of tumor tissue from enrolled participants: surgical samples needed;
- Derivation of lymphoblastoid cell line for complementation testing; maintenance of Fanconi anemia cell and DNA repositories;
- Genetic counseling for individuals involved in the IFAR, and their family members.

Testing Services on Research Protocol:
- Mutation analysis (research)
- FANCD2 western blot (research)

Co-Principal Investigators for the IFAR:
- Farid Boulad, MD, Memorial Sloan-Kettering Cancer Center, New York, NY
  Telephone: 212-639-6684 Fax: 212-717-3555
  Email: bouladf@mskcc.org

- Stella Davies, MBBS, PhD, MRCP, Cincinnati Children’s Hospital Medical Center
  Cincinnati, OH
  Telephone: 513-636-1371 Fax: 513-636-3459
  Email: stella.davies@cchmc.org

- Margaret L. MacMillan, MD, University of Minnesota, Minneapolis, MN
  Telephone: 612-626-2778 Fax: 612-626-2815
  Email: macmi002@umn.edu

- David I. Kutler, MD, Head and Neck Surgeon, Weill Cornell Medical Center/New York Presbyterian Hospital, New York, NY
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  Email: dik2002@med.cornell.edu

Memorial Sloan-Kettering Cancer Center
Part of New York Consortium for Inborn Errors of Hematopoiesis and Immunity (see also, Rockefeller University, New York Presbyterian Hospital, and Hospital for Special Surgery)
1275 York Avenue
New York, NY 10065
Email: www.mskcc.org

- Farid Boulad, MD, Medical Director, Pediatric Day Hospital
  Attending Physician
  Bone Marrow Transplant Service
  Department of Pediatrics
BONE MARROW FAILURE

Services Offered:
- Overall medical and hematological care;
- Hematopoietic stem cell transplantation with related, unrelated, matched or mismatched donors;
- Psychological evaluation and treatment;
- Head and neck cancer evaluation and treatment;
- Gynecological cancer evaluation and treatment;
- Endocrinology clinic;
- Direct collaboration with Dr. Agata Smogorzewska, The Rockefeller University, for mutation screening, complementation group analysis, somatic mosaicism studies, and participation in the International Fanconi Anemia Registry (IFAR);
- Direct collaboration with Dr. Aaron Daluiski at the Hospital for Special Surgery, Pediatric Hand Registry (IFAR);
- Cell biology research on hematopoietic stem cells and progenitor populations in neoplastic and genetic diseases.

Mount Sinai School of Medicine

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Christopher Walsh, MD, Associate Professor of Medicine
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Luis Isola, MD, Director, Stem Cell Transplantation Program
Anne Hurlet-Jensen, MD, Associate Professor of Pediatrics

National Cancer Institute

Clinical Genetics Branch, Division of Cancer Epidemiology and Genetics Clinical Genetics Branch, National Institutes of Health
9609 Medical Center Drive, Room 6E452, MSC 9772
Rockville, MD 20850
www.marrowfailure.cancer.gov

Lisa Leathwood, RN, BSN, Research Nurse and Study Coordinator
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Blanche P. Alter, MD, MPH, FAAP
Telephone: 240-276-7239 Fax: 240-276-7836
Email: alterb@mail.nih.gov

Neelam Giri, MD, FAAP
Telephone: 240-276-7256  Fax: 240-276-7836
Email: girin@mail.nih.gov

Services Offered:
- Comprehensive clinical evaluation by all subspecialties;
- All clinical laboratory tests;
- Cancer screening, age and sex appropriate, such as head, neck and esophagus, and gynecological;
- Bone marrow aspirate, biopsy, and cytogenetics;
- Chromosome breakage studies in a CLIA-certified clinical laboratory;
- Genetic counseling and mutation analysis in a CLIA-certified clinical laboratory;
- Comprehensive evaluation of all immediate family members (with the exception of bone marrow studies);
- Epidemiologic study of cancer in patients and in family members.
BONE MARROW FAILURE

Gynecology Consultation Service at the NIH Clinical Center; Eunice Kennedy Shriver National Institute of Child Health and Human Development
10 Center Dr. Suite 1-3140
Bethesda, MD 20892

- **Pamela Stratton, MD**, Chief, Gynecology Consult Service
  Telephone: 301-496-9079  Fax: 301-480-6703
  Email: strattop@mail.nih.gov

Services Offered:
- Gynecology consulting service is only available to FA patients/family members enrolled in Blanche Alter’s protocol.

Head and Neck Surgery Branch at the NIH
Building 10, Room 4-2732
10 Center Drive
Bethesda, MD 20892

- **Carter Van Waes, MD, PhD**, Chief Head and Neck Surgery Branch
  Clinical Director, National Institute on Deafness and other Communication Disorders
  Telephone: 301-402-4216  Fax: 301-402-1140
  Email: vanwaesc@nidcd.nih.gov

Dermatology Consultation Service at the NIH Clinical Center; Center for Cancer Research
Building 10, Room 12N238
Bethesda, MD 30892-1908

- **Edward Cowen, MD**, Head, Dermatology Consultation Service
  Telephone: 301-496-4299  Fax: 301-402-2943
  Email: cowene@mail.nih.gov

Services Offered:
- Dermatology consulting service is only available to FA patients/family members enrolled in Blanche Alter's protocol.

Oregon Health & Science University
Doernbecher Children’s Hospital
3181 S.W. Sam Jackson Park Road
Portland, OR 97239

- **Peter Kurre, MD**, Professor of Pediatrics
  Telephone: 503-494-1543 Fax: 503-494-0714
  Email: kurrepe@ohsu.edu

- **Evan Shereck, MD**, Associate Professor of Pediatrics
  Telephone: 503-494-0829 Fax: 503-494-0714
  Email: shereck@ohsu.edu

Services Offered:
- Diagnostic evaluation and genetic counseling for FA;
- Comprehensive medical treatment;
- Stem cell transplantation;
- Research studies investigating molecular diagnostics, cytogenetics, complementation group subtyping, leukemogenesis, and genetics of Fanconi anemia.

Stanford School of Medicine
The Bass Center for Childhood Cancer and Blood Diseases
725 Welch Road
Palo Alto, CA 94304
www.stanfordchildrens.org

Pediatric Hematology/Oncology Academic Office
1000 Welch Road, Suite 300
Palo Alto, CA 94304

Hematology/Oncology
Telephone: 650-723-5535

- **Bertil Glader, MD, PhD**, Professor, Pediatrics and Pathology
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- **Michael Jeng, MD**, Associate Professor, Pediatrics
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- **Anu Narla, MD**, Assistant Professor, Pediatrics
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- **Judith Lea, RN, MSN, PNP**, Hematology Nurse Practitioner
  Email: jlea@stanfordchildrens.org

- **Kirsten Mouradian, RN, MSN, FNP**, Hematology Nurse Practitioner
  Email: kmouradian@stanfordchildrens.org

Stem Cell Transplant
Telephone: 650-725-9250

- **Kenneth Weinberg, MD**, Professor, Pediatrics
  Email: kw1@stanford.edu

- **Rajni Agarwal, MD**, Assistant Professor, Pediatrics
  Email: rajnia@stanford.edu
BONE MARROW FAILURE

- **Sandhya Kharbanda, MD.** Assistant Professor, Pediatrics  
  Email: ksandhya@stanford.edu

- **Karen Kristovich, RN, MSN, PNP.** Stem Cell Transplant Nurse Practitioner  
  Email: kkrustovich@stanfordchildrens.org

- **Elizabeth Schnorr, RN, PNP.** Stem Cell Transplant Coordinator  
  Email: eschnorr@stanfordchildrens.org

- **Donna Reimer, RN.** Stem Cell Transplant Coordinator  
  Email: dreimer@stanfordchildrens.org

- **Gayle Humphrey, RN.** Stem Cell Transplant Coordinator  
  Email: ghumphrey@stanfordchildrens.org

**Services Offered:**
- Diagnostic evaluation for Fanconi anemia and other bone marrow failure syndromes;
- Comprehensive care and long-term follow-up of new and previously diagnosed patients;
- Stem cell transplantation with matched related donor, matched unrelated donor, umbilical cord blood, and peripheral blood stem cells.

**Texas Children’s Hospital**

1102 Bates, FC1200  
Houston, TX 77030

- **Alison Bertuch, MD, PhD.**  
  Telephone: 832-824-4579  
  Email: abertuch@txch.org

**University of Minnesota**

Fanconi Anemia Comprehensive Care Program

University of Minnesota Medical Center and Masonic Children's Hospital

MMC 366  
420 Delaware Street, S.E.  
Minneapolis, MN 55455  
Telephone: 612-273-2800  
http://bmt.umn.edu/fanconi-anemia

- **John E. Wagner, MD.** Fanconi Anemia Comprehensive Care Program Leader, Director, Division of Hematology/Oncology and Blood and Marrow Transplantation  
  CCRF/Hageboeck Family Chair in Pediatric Oncology & Clinical Director, Stem Cell Institute  
  Telephone: 612-626-2961  
  Fax: 612-626-4074  
  Email: wagne002@umn.edu

- **Margaret L. MacMillan, MD.** Fanconi Anemia Comprehensive Care Program Leader  
  Associate Professor, Department of Pediatrics, Division of Blood and Marrow Transplantation  
  Telephone: 612-626-2778  
  Fax: 612-626-2815  
  Email: macmi002@umn.edu

- **Jakub Tolar, MD, PhD.** Director, Stem Cell/Gene Therapies  
  Albert and Eva Corniae Chair  
  Associate Professor, Department of Pediatrics, Division of Blood and Marrow Transplantation  
  Telephone: 612-625-2912  
  Fax: 612-624-3913  
  Email: tolar003@umn.edu

- **Anna Petryk, MD.** Pediatric Endocrinology  
  Telephone: 612-624-5409  
  Fax: 612-626-5262  
  Email: petry005@umn.edu

- **Sarah Jane Schwarzenberg, MD.** Pediatric Gastroenterology  
  Telephone: 612-624-1133  
  Fax: 612-626-0639  
  Email: schwa005@umn.edu

- **Frank Ondrey, MD, PhD, FACS.** Otolaryngology  
  Telephone: 612-624-5900  
  Email: ondre002@umn.edu

- **Rahel G. Ghebre, MD.** Gynecologic Oncology  
  Telephone: 612-626-2613  
  Fax: 612-626-0665  
  Email: ghebr004@umn.edu

- **Ann E. Van Heest, MD.** Dept. of Orthopaedic Surgery  
  Telephone: 612-273-8086  
  Fax: 612-273-7959  
  Email: Vanhe003@umn.edu

- **Jo-Anne H. Young, MD.** Infectious Disease  
  Telephone: 612-624-9996  
  Fax: 612-625-4410  
  Email: Vanbu004@umn.edu

- **Pat Fidler, RN.** Nurse Coordinator  
  Telephone: 612-273-8480  
  Fax: 612-273-2919  
  Email: pfidler1@fairview.org

- **Rebecca Tryon, MS, CGC.** Genetic Counseling  
  Telephone: 612-624-1510  
  Fax: 612-624-6645  
  Email: rtryon1@fairview.org

**Journey Clinic**

Center for Pediatric Blood and Marrow Transplantation  
East Building, Ninth Floor  
2450 Riverside Avenue  
Minneapolis, MN 55454  
http://bmt.umn.edu/  
Telephone: 612-273-2800  
Fax: 612-273-2919
Services Offered:
- The University of Minnesota Fanconi Anemia Comprehensive Care Program (FACCP) utilizes a multidisciplinary team approach to ensure that the care we provide is individually tailored to meet the unique needs of each patient and family.
- The FACCP is composed of expert health care providers who specialize in blood and marrow transplantation, hematology, cancer (head and neck, gynecological), infectious disease, neurology, nephrology, cardiology, care partners (volunteer family support), social work, genetics, voice reconstruction (to treat androgen side effects), nutrition therapy, orthopedic surgery, endocrinology (diabetes, short stature), dietician, gastroenterology, gynecology and fertility counseling, and radiation therapy;
- Consultations with new and previously diagnosed Fanconi anemia patients;
- Individualized treatment planning for newly diagnosed children and adults who do not need transplant;
- Blood and marrow transplantation: expertise in unrelated marrow and umbilical cord transplantation and matched sibling donor transplantation for Fanconi anemia with a 24-bed pediatric inpatient unit in the new Children’s Hospital and a 30-bed adult inpatient unit and state of the art outpatient bone marrow transplantation clinic;
- Genetic counseling and coordination of complementation group analysis, mutation screening, somatic mosaicism studies, and other genetic testing options including prenatal genetic testing and pre-implantation genetic diagnosis (PGD);
- Family support services including nurse coordination, social work, genetic counseling, care-partners, and child and family life specialists to assist families throughout the diagnostic, transplantation, and post-transplantation processes;
- Family umbilical cord blood banking;
- Ongoing research in stem cell biology, mosaicism, genetic correction of stem cells, mechanisms of bone marrow failure, and novel treatments with collaborators around the country.

University of Texas Southwestern Medical Center
Pediatric Bone Marrow Failure Program
Children’s Health Dallas
Margaret Allen Gill Center for Cancer and Blood Disorders
1935 Medical District Drive
Dallas, TX 75235
Telephone: 214-456-2382 or 214-456-6102
Email: BoneMarrowFailure@UTSouthwestern.edu

- Zora R. Rogers, MD, Professor of Pediatrics, Hematology-Oncology, Clinical Director, Hematology and Bone Marrow Failure Program
Email: zora.rogers@utsouthwestern.edu

- Tiffany Simms-Waldrip, MD, Assistant Professor of Pediatrics, Hematology-Oncology
Head, Bone Marrow Failure Stem Cell Transplant Program
Email: tiffany.simms-waldrip@utsouthwestern.edu

Services Offered:
- Consultation and education for new and previously diagnosed patients and their families;
- Comprehensive clinical management of pediatric Fanconi anemia patients;
- Stem cell transplantation for Fanconi anemia; stem cell collection and reinfusion;
- Disease based follow-up post transplantation for Fanconi anemia;
- Coordinated referral to institutional subspecialists in cardiology, endocrinology, gastroenterology, dental/oral-maxillo-facial surgery, nephrology, hand and orthopedic surgery interested in the unique needs of persons with Fanconi anemia;
- Psychology, social work, physical and occupational therapy services.
Delete Blood Cancer DKMS
100 Broadway, 6th Floor
New York, NY 10005
www.dkmsamericas.org
Telephone: 1-866-340-3567
Email: info@dkmsamericas.org

Delete Blood Cancer DKMS is committed to the fight against blood diseases like leukemia and Fanconi anemia, and strives to give every blood cancer patient a second chance at life by recruiting bone marrow donors from every race and ethnicity. We inspire hope by matching our donors with patients from around the world who are in need of a bone marrow transplant.

Delete Blood Cancer DKMS:
- is the world’s largest bone marrow donor center, with more than 3 million registered donors;
- can register new bone marrow donors anywhere in the U.S;
- performs HLA- A*, B*, C*, DR* high-resolution typing on every registered donor, minimizing the search time for finding the best possible donor match for a patient;
- offers doctors immediate search of our database;
- does not require new donors to pay the $65 registration fee.

National Marrow Donor Program®/Be The Match®
3001 Broadway Street NE
Minneapolis, MN 55413-1753
www.bethematch.org
Telephone: 1-888-999-6743
Outside of the U.S: 612-632-3410
Email: patientinfo@nmdp.org

Be The Match helps patients with leukemia, lymphoma and other diseases who need a marrow or umbilical cord blood transplant. People can join the Be The Match Registry® - the world’s largest listing of potential marrow donors and donated cord blood units - contribute financially, and volunteer. Patients and their families can also turn to Be The Match for support and resources before, during, and after transplant. Be The Match is operated by the National Marrow Donor Program® (NMDP), a nonprofit organization that matches patients with donors, educates health care professionals, and conducts research so more lives can be saved. Learn more at BeTheMatch.org/patient.

Services Offered:
Be The Match has a team dedicated to supporting patients, caregivers and families before, during, and after transplant. We offer confidential one-on-one support, financial guidance, and free educational resources. Our goal is to get you what you need, when you need it. We offer support in more than 100 languages, including Spanish bilingual staff and translated materials.

Cord Blood Registry®
Designated Treatment Program (DTP)
Cord Blood Registry
1200 Bayhill Drive, 3rd Floor
San Bruno, CA 94066
www.cordblood.com
Telephone: 1-888-932-6568

Cord Blood Registry® (CBR) is the world’s largest and most experienced family cord blood and tissue stem cell bank.

Families wishing to store their newborn’s umbilical cord blood stem cells for a family member diagnosed with a life-threatening disease treatable by donor stem cells (including Fanconi anemia) are encouraged to apply for CBR’s Designated Treatment Program. If eligible, CBR will provide the collection kit and process and store the newborn’s cord blood and cord tissue sample for five years without any cost to the family. The family member must be a first-degree blood relative (full-sibling or parent) to the newborn and have an oncologist/hematologist or other treating physician agree that the stem cells can be used for treatment.
**DERMATOLOGY**

**National Cancer Institute**
Clinical Genetics Branch, Division of Cancer Epidemiology and Genetics Clinical Genetics Branch, National Institutes of Health
9609 Medical Center Drive, Room 6E452, MSC 9772
Rockville, MD 20850
[www.marrowfailure.cancer.gov](http://www.marrowfailure.cancer.gov)

Dermatology Consultation Service at the NIH Clinical Center; Center for Cancer Research
Building 10, Room 12N238
Bethesda, MD 30892-1908

- **Edward Cowen, MD.** Head, Dermatology Consultation Service
  Telephone: 301-496-4299  Fax: 301-402-2943
  Email: cowene@mail.nih.gov

**Services Offered:**
- Dermatology consulting service is only available to FA patients/family members enrolled in Blanche Alter's protocol.

**Brigham and Women’s Hospital**
Brigham Dermatology Associates
221 Longwood Avenue
Boston, MA 02115

- **Jennifer Lin, MD.**
  Telephone: 617-732-4918  Fax: 617-582-6060
  Email: jylin@partners.org

**ENDOCRINOLOGY**

**Cincinnati Children’s Hospital Medical Center**
Fanconi Anemia Comprehensive Care Center
3333 Burnet Avenue
Cincinnati, OH 45229

- **Susan R. Rose, MD, MEd.** Professor of Pediatrics, Pediatric Endocrinology
  Telephone: 513-636-4744
  Email: susan.rose@cchmc.org

**University of Minnesota**
Fanconi Anemia Comprehensive Care Program
University of Minnesota Medical Center and Masonic Children's Hospital
East Bldg Rm MB671
2450 Riverside Avenue
Minneapolis, MN 55454

- **Anna Petryk, MD.** Pediatric Endocrinology
  Telephone: 612-624-5409 Fax: 612-626-5262
  Email: petry005@umn.edu
Cincinnati Children’s Hospital Medical Center
Fanconi Anemia Comprehensive Care Center
3333 Burnet Avenue
Cincinnati, OH 45229

- Samuel Kocoshis, MD, Professor
  Telephone: 513-636-4415
  Email: samuel.kocoshis@cchmc.org

University of Minnesota
Fanconi Anemia Comprehensive Care Program
University of Minnesota Medical Center and
Masonic Children's Hospital
East Building, 6th Floor
2450 Riverside Avenue
Minneapolis, MN 55454

- Sarah Jane Schwarzenberg, MD, Director, Pediatric Gastroenterology, Hepatology and Nutrition
  Telephone: 612-624-1133  Fax: 612-626-0639
  Email: schwa005@umn.edu

The Rockefeller University
Part of New York Consortium for Inborn Errors of Hematopoiesis and Immunity (see also, Memorial Sloan Kettering Cancer Center, New York Presbyterian Hospital, and Hospital for Special Surgery)
1230 York Avenue Box 182
New York, NY 10065
Fax: 212-327-8262
Facebook: Fanconi Anemia Registry or Agata Smogorzewska (PI of IFAR)

- Jennifer Kennedy, MS, CGC, Certified Genetic Counselor*
  Telephone: 212-327-8612
  Email: jkennedy@rockefeller.edu

*Genetic counseling provided for IFAR participants and their family members. Please see page 6 for more information about IFAR.

Journey Clinic
Center for Pediatric Blood and Marrow Transplantation
East Building, Ninth Floor
2450 Riverside Avenue
Minneapolis, MN 55454
Website: http://bmt.umn.edu/world-class-bmt-program/fanconi-anemia.php
Telephone: 612-273-2800  Fax: 612-273-2919

- Rebecca Tryon, MS, CGC
  Telephone: 612-624-1510  Fax: 612-624-6645
  Email: rtryon1@fairview.org
GYNECOLOGY

Eunice Kennedy Shriver National Institute of Child Health and Human Development
Bldg 10, CRC, Room 1-3140
10 Center Dr. MSC 1109
Bethesda, MD 20892-1109

- Pamela Stratton, MD, Chief, Gynecology Consult Service, Program in Reproductive and Adult Endocrinology
  Telephone: 301-496-9079 Fax: 301-480-6703
  Email: strattop@mail.nih.gov

University of Minnesota
Fanconi Anemia Comprehensive Care Program
University of Minnesota Medical Center, Masonic Children’s Hospital, Fairview
MMC 366, University of Minnesota
420 Delaware Street, S.E.
Minneapolis, MN 55455

- Rahel G. Ghebre, MD, Gynecologic Oncology
  Telephone: 612-626-2613 Fax: 612-626-0665
  Email: ghebr004@umn.edu

The New York Presbyterian Hospital
Weill Cornell Medical Associates
Part of New York Consortium for Inborn Errors of Hematopoiesis and Immunity (see also, Memorial Sloan Kettering Cancer Center, The Rockefeller University, and Hospital for Special Surgery)
2315 Broadway
New York, NY 10024
Telephone: 212-241-6000
Fax: 212-241-6001

- Mercedes Castiel, MD, Gynecology
  Telephone: 646-962-2110
  Email: mec9109@med.cornell.edu

Services Offered:
Gynecological cancer evaluation and treatment.

HAND SURGEONS

Ann Van Heest, MD, Professor
- University of Minnesota, Department of Orthopaedic Surgery
  2450 Riverside Avenue, Rm R200
  Minneapolis, MN 55454
  Telephone 612-273-8086
  Email: vanhe003@umn.edu

- Gillette Children’s Speciality Healthcare
  200 University Avenue East
  St. Paul, MN 55101
  Telephone: 651-291-2848

- Shriner’s Hospital for Children, Twin Cities Unit
  2025 East River Parkway
  Minneapolis, MN 55414
  Telephone: 612-596-6100

Services Offered:
- Hand and upper extremity surgery in the pediatric population.

Cincinnati Children’s Hospital Medical Center
Fanconi Anemia Comprehensive Care Center
3333 Burnet Avenue
Cincinnati, OH 45229

- Roger Cornwall, MD, Associate Professor of Pediatrics, Division of Orthopaedics (Hand Surgery)
  Telephone: 513-803-HAND Fax: 513-636-3928
  Email: roger.cornwall@chmc.org
HAND SURGEONS, cont’d

Hospital for Special Surgery
Part of New York Consortium for Inborn Errors of Hematopoiesis and Immunity (see also, Memorial Sloan Kettering Cancer Center, The Rockefeller University, and The New York Presbyterian Hospital)
535 E 70th Street, 5th Floor
New York, NY 10065

- Aaron Daluiski, MD, Orthopedics – Hand and Upper Extremity Surgery, Lerners Children’s Pavilion
  Telephone: 212-606-1284

University of Virginia Health System
- A. Bobby Chhabra, MD, Professor and Chair Department of Orthopaedic Surgery
  Lillian T. Pratt Distinguished Professor of Orthopaedic Surgery
  Professor of Plastic and Reconstructive Surgery
  Telephone: 434-243-0218 Fax: 434-243-0290
  Appointments: 434-982-4263
  Email: A2H@hscmail.mcc.virginia.edu

Services Offered:
- Surgery for congenital hand and upper extremity differences.

Shriners Hospital for Children
3551 North Broad Street
Philadelphia, PA 19140

- Scott Kozin, MD, Chief of Staff, Shriners Hospital for Children Philadelphia, Professor, Orthopedic Surgery, Temple University
  Telephone: (215) 430-4034
  Email: skozin@shrinenet.org

- Linda Filipone, Nurse Coordinator
  Telephone: (215) 430-4074
  Email: lfilipone@shrinenet.org

- Maureen Fulcher, Nurse Assistant
  Telephone: (215) 430-4204
  Email: mfulcher@shrinenet.org

Services Offered:
- Evaluation and treatment of FA children with upper limb and other orthopedic problems;
- Surgical expertise in hand and upper limb differences;
- Occupational therapy evaluation and treatment, including splints, adaptive equipment, and other needs.

OPHTHALMOLOGY

Boston Foundation for Sight
464 Hillside Avenue, Suite 205
Needham, MA 02494
www.bostonsight.org

- Gillian Fontana, New Patient Affairs Coordinator
  Telephone: 781-726-7501 Fax: 781-726-7310
  Email: GFontana@bostonsight.org

Boston Foundation for Sight is a non-profit organization with a mission to improve the quality of life for patients and their families by transforming the understanding, treatment, and care of complex corneal disease.

Services Offered:
BostonSight® PROSE treatment is a process by which visual function is restored to a patient with complex corneal disease, enabling them to reclaim their life. During PROSE treatment, doctors customize prosthetic devices to replace or support impaired ocular surface functions, improving vision and reducing pain and light sensitivity.
Cincinnati Children’s Hospital Medical Center
Fanconi Anemia Comprehensive Care Center
3333 Burnet Avenue
Cincinnati, OH 45229

- Michael Rutter, MD, Professor of Pediatrics, Division of Otolaryngology
  Telephone: 513-636-4356 Fax: 513-636-8133
  Email: mike.rutter@cchmc.org

Cornell University, Weill Medical College
Department of Otolaryngology-Head and Neck Surgery
1305 York Avenue, 5th Floor
New York, NY 10021

- David Kutler, MD, Associate Professor
  Telephone: 646-962-4323
  Email: dik2002@med.cornell.edu

Clinical Interests: Head and neck cancer in Fanconi anemia patients, tongue cancer, disorder of nasal sinus, skull base surgery, pharynx, thyroid cancer, benign tumor of oral cavity, thyroid surgery, head and neck cancer surgery, and salivary disorder.

Johns Hopkins Medical Institutions
601 N. Caroline Street, 6th Floor
Baltimore, MD 21287-0910

- Joseph Califano, MD, Professor, Otolaryngology, Head & Neck Surgery & Head & Neck Research Division
  Telephone: 410-955-6420 Fax: 410-955-8510
  Email: jcalifa@jhmi.edu

Clinical Interests: Tumors of the oral cavity, larynx, pharynx, neck, skull base, salivary glands, thyroid cancer, premalignant conditions of the upper aerodigestive tract, and unknown primary head and neck squamous cell carcinoma, skin cancer and melanoma.

Memorial Sloan-Kettering Cancer Center
1275 York Avenue
New York, NY 10021

- Bhuvanesh Singh, MD, PhD, Head and Neck Cancer
  Telephone: 212-639-2024
  Email: singhb@mskcc.org

Clinical Interests: All head and neck cancers, with a particular focus on cancers of the mouth (tongue, floor of mouth, and buccal mucosa), skull base, and salivary and thyroid glands, as well as melanomas and skin cancers of the head and neck region.

National Institutes of Health
NIDCD/NIH
10 Center Drive, Building 10
Bethesda, MD 20892

- H. Jeffrey Kim, MD, Senior Staff Clinician, Head and Neck Surgery Branch, National Institute on Deafness and Other Communication Disorders
  Professor, Department of Otolaryngology, Head and Neck Surgery, Georgetown University Hospital
  Telephone: 301-496-5369 Fax: 301-402-0409
  Email: kimj@niddc.nih.gov

Clinical Interests: Dizziness, hereditary hearing loss, balance disorders, acoustic neuroma and skull base surgery, otosclerosis, cholesteatoma.

- Carter Van Waes, MD, PhD, Chief Head and Neck Surgery Branch; Clinical Director, National Institute on Deafness and other Communication Disorders
  Telephone: 301-402-4216 Fax: 301-402-1140
  Email: vanwaesc@niddc.nih.gov

Clinical Interests: Diagnosis and investigational treatment of head and neck mucosal lesions and cancers.

University of California at San Francisco
CTSI, Box 0558
550 16th Street, 6th Floor
San Francisco, CA 94158-2549

- Jennifer Rubin Grandis, MD, FACS
  Telephone: 415-514-8084
  Email: Jennifer.Grandis@ucsf.edu

Specialty: Otolaryngology
Sub Specialty: Head and neck surgery

University of Chicago
5841 S. Maryland Avenue, MC6092
Chicago, IL 60634

- Everett Vokes, MD, John E. Ultmann Professor, Chairman, Department of Medicine, Physician-in-Chief, University of Chicago Medicine and Biological Sciences
  Telephone: 773-702-9306 Fax: 773-702-4427
  Email: evokes@medicine.bsd.uchicago.edu

Clinical Interests: Hematology, oncology, head and neck cancer, and lung cancer.
• Tanguy Seiwert, MD, Assistant Professor of Medicine  
  Telephone: 773-702-2452  Fax: 773-702-3002  
  Clinical Interests: Head and neck cancer and lung cancer.

University of Cincinnati, College of Medicine  
Department of Otolaryngology  
P.O. Box 670528  
Cincinnati, OH 45267  
• Keith A. Casper, MD, Assistant Professor  
  Telephone: 513-475-8400  Fax: 513-558-4477  
  Email: Keith.casper@uc.edu  
• Keith M. Wilson, MD  
• Lee A. Zimmer, MD

University of Minnesota  
Fanconi Anemia Comprehensive Care Program  
University of Minnesota Medical Center and  
Masonic Children's Hospital  
MMC 396, University of Minnesota  
420 Delaware Street, SE  
Minneapolis, MN 55455  
• Frank Ondrey, MD, PhD, FACS, Associate Professor  
  of Otolaryngology, Director, Molecular Oncology Program  
  Telephone: 612-624-5900  
  Email: ondre002@umn.edu  
Clinical Interests: Head and neck cancer, precancerous mouth and throat lesions, comprehensive general otolaryngology, and facial trauma.

University of Texas Health Science Center  
at Houston  
Department of Otorhinolaryngology - Head & Neck Surgery  
6400 Fannin, Suite 2700  
Houston, TX 77030  
• Ron J. Karni, MD, Assistant Professor of  
  Otolaryngology, Assistant Professor of Medical Oncology  
  Telephone: 713-486-5000 and 713-500-5410  
  Email: ron.j.karni@uth.tmc.edu  
Clinical Interest: Head and neck cancer, robotic, and minimally-invasive surgery of the head and neck.  
Services Offered: Management of head and neck cancer including surgery, chemotherapy, and radiation oncology.

University of Texas MD Anderson  
Cancer Center  
1515 Holcombe Boulevard, Unit 1445  
Houston, TX 77030  
• Erich Madison Sturgis, MD, MPH, FACS, Professor of  
  Surgery, Professor of Epidemiology  
  Telephone: 713-792-5432  Fax: 713-794-4662  
Clinical Interests: Head and neck cancer, salivary carcinoma, and thyroid cancer, human papillomavirus, and sarcomas of the head and neck.  
Services Offered: Multi-disciplinary evaluation and treatment of head and neck tumors.
Pre-implantation Genetic Diagnosis

Genesis Genetics
705 S. Main Street
Plymouth, MI 48170
www.genesisgenetics.org

- John Kitchen, PhD
  Telephone: 313-579-9650  Fax: 313-544-4006

- Elizabeth Cameron, MS, CGC, Certified Genetic Counselor
  Telephone: 313-579-9650  Fax: 313-544-4006
  Email: counselor@genesisgenetics.org

- Jeannie Klavanian, MS, Genetic Counselor
  Telephone: 313-579-9650  Fax: 313-544-4006

Services Offered:
- Pre-pregnancy/pre-implantation diagnosis for Fanconia anemia (including types A, C, D2, F, G, I, and J, among others). Helping a couple begin a pregnancy knowing their baby will not have Fanconi anemia.
- Extensive experience in Fanconi anemia mutation testing with HLA identity matching for families desiring a healthy baby and cord blood stem cells that are a perfect match to their Fanconi anemia-affected child needing stem cell transplantation.
- Personalized treatment regimens coordinated with the family’s hematologist, geneticist, obstetrician, and (if necessary) transplantation doctors. The FA family does not need to travel for these PGD services. Our clinic collaborates with the leading molecular biologists in Fanconi anemia research, with over 230 in vitro fertilization programs, and with internationally respected Fanconi anemia transplantation experts.

Reproductive Genetic Innovation
2910 MacArthur Boulevard
Northbrook, IL 60062
Telephone: 847-400-1515
www.rgipgd.com
Email: info@rgipgd.com

- Stephanie Peters, MGC, CGC
- Divya Shah, MS, LCGC
- Agnes Machaj, MS

Services Offered:
- Pre-implantation genetic diagnosis for any known Fanconi anemia mutations with or without HLA matching for sibling bone marrow donation;
- Pioneers in PGD; first laboratory in the world to successfully perform PGD for FA and HLA matching. Highly accurate state-of-the-art testing methods;
- Able to test for chromosomal abnormalities in addition to FA and HLA on a single cell from an embryo;
- Free consultations with genetic counselors (in-person or via telephone);
- Travel to our facility is not necessary as we collaborate with hundreds of in vitro fertilization clinics all over the world.

Radiation Oncology

University of Pittsburgh Cancer Institute
UPMC Cancer Pavilion, POB 2
5150 Centre Avenue
Pittsburgh, PA 15232

- Joel Greenberger, MD
  Telephone: 412-647-3602
  Email: greenbergerj@upmc.edu

Clinical Interests:
- Radiation sensitivity in Fanconi anemia

Services Offered:
- Consultation (telephone, email, in person) with families and physicians regarding the use of radiation in a person with Fanconi anemia.
- Treat patients diagnosed with cancer by utilizing various forms of radiation therapy.