

U.S. Fanconi Anemia Treatment Resource Guide

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.

BONE MARROW FAILURE

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 Tchong, 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. Mehlman, MD**, Director, Musculoskeletal Outcomes Research
Co-Director, Brachial Plexus Center
Professor, Division of Pediatric Surgery
Telephone: 513-636-4785 Fax: 513-803-3928
Email: charles.mehlman@cchmc.org
- **Parinda Mehta, MD**, Associate Professor, UC Department of Pediatrics
Telephone: 513-636-4913 Fax: 513-803-1969
Email: parinda.mehta@cchmc.org
- **Eugene Minevich, MD, FACS, FAAP**, Director, Stone Program
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@cchmc.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
Email: sarmenian@coh.org
- **Julie Wolfson, MD**, Staff Physician, Pediatrics; Assistant Professor, Population Sciences & Pediatrics
Email: jwolfson@coh.org
- **Debbie Hitt, RN, BSN, CPHON**, Nurse-Coordinator, Pediatric Hematology/Hematopoietic Cell Transplantation
Email: jwolfson@coh.org

- **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: reortiz@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

Services Offered:

- Diagnostic testing and screenings of siblings;
- Complete evaluation, treatment and follow-up of new and previously diagnosed FA patients;
- Information and assistance for physicians in the care of their FA patients;
- Cancer screening and specialist consultations;
- Hematopoietic stem cell transplantation from siblings, matched unrelated donors and umbilical cord blood units;
- Long-term, Fanconi anemia-focused, post-transplant follow-up.

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

BONE MARROW FAILURE

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 stem 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.
- Facilitation of DNA mutation identification via CAP/CLIA-certified DNA sequencing in the Laboratory Medicine Department at Boston Children's Hospital coordinated with Dr. Bai-Lin Wu and Ann Reinhard. Current available testing for *FANCA*, *FANCC*, and *FANCG* are listed at www.genetests.org. Genetic Counselor: Ann E. Reinhard, MS, CGC, phone: 617-355-4907, ann.reinhard@childrens.harvard.edu.
- 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.fhcr.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
Investigator, Markey Molecular Medicine Center
Adjunct Associate Professor of Pathology
Associate Professor of Medicine, University of Washington School of Medicine
Telephone: 206-667-4425 Fax: 206-667-6124
Email: hkiem@fredhutch.org
- **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
Telephone: 206-987-2106 Fax: 206-667-5899
Email: ksbaker@fredhutch.org
- **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
Telephone: 206-667-4453 Fax: 206-667-4310
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).

BONE MARROW FAILURE

Hackensack University Medical Center **Tomorrow's Children Institute**

30 Prospect Avenue
Hackensack, NJ 07601
www.HackensackUMC.org

- **Alfred P. Gillio, MD**, Director, Blood and Marrow Transplantation Program
Joseph M. Sanzari Children's Hospital
Institute of Pediatric Cancer & Blood Disorders at
Hackensack University Medical Center
Telephone: 551-996-5600 Fax: 551-996-0521
Email: agillio@hackensackumc.org
- **Barbara Adler-Brecher, MS**
Email: badler-brecher@hackensackumc.org

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: auerbac@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
Telephone: 646-962-4323, 646-962-0100
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

Telephone: 212-639-6684 Fax: 212-717-3555

Email: bouladf@mskcc.org

- **Bhuvanesh Singh, MD, PhD**, Head and Neck Cancer
Telephone: 212-639-2024
Email: singhb@mskcc.org
- **Julia A. Kearney, MD**, Psychiatry and Pediatrics
Telephone: 646-888-0028
Email: Kearneyj@mskcc.org
- **Jennifer Kennedy, MS, CGC**, Genetic Counselor/Study Coordinator
Telephone: 646-888-4102
Email: Kennedyj@mskcc.org
- **Mercedes Castiel, MD**, Gynecology
Telephone: 646-962-2110
Email: mec9109@med.cornell.edu

Services Offered:

- Comprehensive care and long-term follow-up of new and previously diagnosed patients, including:
- 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

Novel Therapeutics and Stem Cell Transplantation Program
Division of Hematology-Oncology
Annenberg 24-42, Box 1079
One Gustave L. Levy Place
New York, NY 10029

- **Christopher Walsh, MD**, Associate Professor of Medicine
Telephone: 212-241-3443
Email: christopher-e.walsh@msnyuhealth.org

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

Services Offered:

- Adult and pediatric FA patients can be seen by specialists in adult medicine and pediatrics;
- Complete hematologic evaluation/treatment and cancer surveillance;
- Recommendations for stem cell transplantation (related and unrelated donor) at Mount Sinai School of Medicine and elsewhere.

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.marrowsfailure.cancer.gov

- **Lisa Leathwood, RN, BSN**, Research Nurse and Study Coordinator
Telephone: 301-212-5250 and 800-518-8474
Fax: 301-212-5281
Email: lisleathwood@westat.com
- **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
Email: bglader@stanford.edu
- **Michael Jeng, MD**, Associate Professor, Pediatrics
Email: mjeng@stanford.edu
- **Anu Narla, MD**, Assistant Professor, Pediatrics
Email: anunarla@stanford.edu
- **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: kkristovich@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
- **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 Corniea 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

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

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

BONE MARROW FAILURE

Services Offered:

- The University of Minnesota Fanconi Anemia Comprehensive Care Program (FACCP) utilizes a multi-disciplinary 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-Waldrup, MD**, Assistant Professor of Pediatrics, Hematology-Oncology
Head, Bone Marrow Failure Stem Cell Transplant Program
Email: tiffany.simms-waldrup@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.

BONE MARROW DONOR REGISTRIES

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 REGISTRIES

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.marrowsfailure.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

GASTROENTEROLOGY

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

GENETIC COUNSELING

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: stratton@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: 214-456-2382 or 214-456-6102

- **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 Specialty Healthcare
200 University Avenue East
St. Paul, MN 55101
Telephone: 651-291-2848

- Shriners 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@cchmc.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, Lerner 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: AC2H@hscmail.mcc.virginia.edu
Websites: <http://uvaortho.com/chhabra>
<http://orthodoc.aaos.org/bobbychhabra/>

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.

OTOLARYNGOLOGY (Ear, Nose, and Throat) and HEAD & NECK CANCER

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@nidcd.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@nidcd.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. Ulmann 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.

OTOLARYNGOLOGY (Ear, Nose, and Throat) and HEAD & NECK 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 Fanconi 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: greenbergerjs@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.