

# US 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.

## BONE MARROW FAILURE

### Children's Hospital Boston & Dana-Farber Cancer Institute The Fanconi Anemia and Bone Marrow Failure Multidisciplinary Clinic

#### Children's Hospital Boston

300 Longwood Ave.  
Boston, MA 02115

<http://www.childrenshospital.org/fa-bmf>

- **David A. Williams, MD**  
Telephone: 617-919-2697  
E-mail: [dawilliams@childrens.harvard.edu](mailto:dawilliams@childrens.harvard.edu)
- **Colin Sieff, MB BCh**  
Telephone: 617-355-2984  
E-mail: [colin.sieff@childrens.harvard.edu](mailto:colin.sieff@childrens.harvard.edu)
- **Tara Barlow, PA**  
**Program Coordinator**  
Telephone: 617-355-8246 Fax: 617-730-0641  
E-mail: [fa-bmf@childrens.harvard.edu](mailto:fa-bmf@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  
E-mail: [alan\\_dandrea@dfci.harvard.edu](mailto:alan_dandrea@dfci.harvard.edu)
- **Lisa A. Moreau, MS, CLSpCG**  
Telephone: 617-632-6302  
E-mail: [lisa\\_moreau@dfci.harvard.edu](mailto: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; Tara Barlow, PA-C
- 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: Susan Robinson, LICSW
- Urology: Hiep (Bob) Nguyen, MD

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## **BONE MARROW FAILURE, cont'd**

### **Children's Hospital Boston & Dana-Farber Cancer Institute, cont'd**

#### **Services Offered:**

- ◆ Our Program Coordinator 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 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 Children's Hospital Boston coordinated with Dr. Bai-Lin Wu and Ann Reinhard. Current available testing for FANCA, FANCC, and FANCG are listed at [www.genetests.org](http://www.genetests.org). Genetic Counselor: Ann E. Reinhard, MS, CGC, phone: 617-355-4907, [ann.reinhard@childrens.harvard.edu](mailto: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.

### **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  
E-mail: [nkapoor@chla.usc.edu](mailto:nkapoor@chla.usc.edu)

## BONE MARROW FAILURE, cont'd

### **Children's Hospital Central California**

9300 Valley Children's Place  
Madera, California 93636

#### **Department of Pediatric Hematology**

Telephone: (559) 353-5460      Fax: (559) 353-5095

- J. Daniel Ozeran, MD, PhD, Interim Director, Hematology/Oncology
- Faisal Razzaqi, MD
- Wendy Tcheng, MD
- Ruetima Titaphiwatanakun, MD
- Terea Giannetta, RN CPNP
- William Koole, Pharm.D
- Frances Patterson, RN, Clinical Coordinator
- Nancy G. Hatcher, MSW, Clinical Social Worker
- Torri Miller, PhD, Clinical Psychologist
- Pamela Young, RD
- Mary Beth Jones, Child Life Coordinator

#### **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, 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, Behavioural Health Sciences and other specialty services. Patients with Fanconi Anemia are provided supportive, educational and concrete services to further enhance care.

### **Children's Hospital of Wisconsin**

MACC Fund Research Center, Suite 3  
8701 Watertown Plank Road  
Milwaukee, WI 53226

- **Monica Thakar, MD**  
Telephone: 414-456-4170    Fax: 414-456-6543  
E-mail: [mthakar@mcw.edu](mailto: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;

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## BONE MARROW FAILURE, cont'd

### Children's Hospital of Wisconsin, cont'd

- ◆ 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.

### Cincinnati Children's Hospital Medical Center, The Fanconi Anemia Comprehensive Care Center

3333 Burnet Ave.

Cincinnati, OH 45229

[www.cincinnatichildrens.org](http://www.cincinnatichildrens.org)

- **Robin Mueller, RN**, Nurse Coordinator, Fanconi Anemia Comprehensive Care Center, Division of Bone Marrow Transplantation and Immune Deficiency, Cancer and Blood Diseases Institute  
Telephone: 513-636-3218 Fax: 513-636-7951  
E-mail: [robin.mueller@cchmc.org](mailto:robin.mueller@cchmc.org)
- **Lisa Vormohr, RN**, Nurse Coordinator, Fanconi Anemia Comprehensive Care Center, Division of Bone Marrow Transplantation and Immune Deficiency, Cancer and Blood Diseases Institute  
Telephone: 513-636-3218 Fax: 513-636-7951.
- **Stella Davies, MB BS, PhD, MRCP**, Jacob G. Schmidlapp Endowed Chair and Professor of Pediatrics, University of Cincinnati College of Medicine, Director, Division of Bone Marrow Transplantation and Immune Deficiency, Cancer and Blood Diseases Institute  
Telephone: 513-636-1371 Fax: 513-636-3549  
E-mail: [stella.davies@cchmc.org](mailto:stella.davies@cchmc.org)
- **Parinda Mehta, MD**, Associate Professor of Pediatrics, Division of Bone Marrow Transplantation and Immune Deficiency, Cancer and Blood Diseases Institute  
Telephone: 513-636-5917 Fax: 513-636-3549  
E-mail: [parinda.mehta@cchmc.org](mailto:parinda.mehta@cchmc.org)
- **Kasiani Myers, MD**, Instructor of Clinical Pediatrics, Division of Bone Marrow Transplantation and Immune Deficiency, Cancer and Blood Diseases Institute  
Telephone: 513- 803-3218 Fax: 513-636-7951  
E-mail: [kasiani.myers@cchmc.org](mailto:kasiani.myers@cchmc.org)
- **Richard Harris, MD**, Professor of Pediatrics, Director of the Bone Marrow Failure Program, Division of Bone Marrow Transplantation and Immune Deficiency, Cancer and Blood Diseases Institute  
Telephone: 513-636-8610 Fax: 513-636-7951  
E-mail: [richard.harris@cchmc.org](mailto:richard.harris@cchmc.org)
- **Susan R. Rose, MD, MEd**, Professor of Pediatrics, Pediatric Endocrinology  
Telephone: 513-636-4744  
E-mail: [susan.rose@cchmc.org](mailto:susan.rose@cchmc.org)

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## BONE MARROW FAILURE, cont'd

### Cincinnati Children's Hospital Medical Center, cont'd

- **Meilan Rutter, MD**, Associate Professor of Pediatrics, Division of Endocrinology  
Telephone: 513-636-4744  
E-mail: [meilan.rutter@cchmc.org](mailto:meilan.rutter@cchmc.org)
- **Michael Rutter, MD**, Associate Professor of Pediatrics, Division of Otolaryngology  
Telephone: 513-636-4881 Fax: 513-636-8133  
E-mail: [mike.rutter@cchmc.org](mailto:mike.rutter@cchmc.org)
- **Nada Yazigi, MD**, Assistant Professor of Pediatrics, Pediatric Gastroenterology  
Telephone: 513-636-4415 Fax: 513-636-7805  
E-mail: [nada.yazigi@cchmc.org](mailto:nada.yazigi@cchmc.org)
- **Jill Huppert, MD, MPH**, Pediatric and Adolescent Gynecology  
Telephone: 513-636-2911 Fax: 513-636-8844  
E-mail: [jill.huppert@cchmc.org](mailto:jill.huppert@cchmc.org)
- **Roger Cornwall, MD**, Assistant Professor of Pediatrics, Division of Orthopaedics (Hand Surgery)  
Telephone: 513-803-HAND Fax: 513-636-3928  
E-mail: [roger.cornwall@cchmc.org](mailto:roger.cornwall@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 (such as with cytokines and novel androgens);
- ◆ 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;
- ◆ Collaborator, International Fanconi Anemia Registry (**Arleen Auerbach, PhD**).

## BONE MARROW FAILURE, cont'd

### City Of Hope

1500 E. Duarte Rd.

Duarte, CA 91010

Telephone: 626-301-8442

E-mail: [jrosenthal@coh.org](mailto:jrosenthal@coh.org)

- **Joseph Rosenthal, MD**, Chair, Pediatrics, member, Pediatric Hematology/Hematopoietic Cell Transplantation
- **Anna Pawlowska, MD**, Director, Pediatric Hematology/Hematopoietic Cell Transplantation  
E-mail: [APawlowska@coh.org](mailto:APawlowska@coh.org)
- **Debbie Hitt, RN**, Nurse-Coordinator, Pediatric Hematology/Hematopoietic Cell Transplantation
- **Nadia Ewing, MD**, Director, Pediatric Hematology
- **April Sorrell, MD**, Pediatric Hematology/Hematopoietic Cell Transplantation and Pediatric Clinical Cancer Genetics
- **Julie Wolfson, MD**, Pediatric Hematology/Hematopoietic Cell Transplantation
- **Joyce Collins, PhD**, Cytogenetics
- **Smita Bhatia, MD**, Pediatrics, Hematology/Hematopoietic Cell Transplantation and Director, Population Sciences
- **Christina Cabanillas, LCSW**, Social Worker, Pediatric Hematology/Hematopoietic Cell Transplantation

### 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;
- ◆ Genetic counseling;
- ◆ 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 Ave., Rm. 225

New Hyde Park, New York 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  
E-mail: [avlachos@lij.edu](mailto:avlachos@lij.edu)

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## BONE MARROW FAILURE, cont'd

### Cohen Children's Medical Center of New York, cont'd

- **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  
E-mail: [jliu3@nshs.edu](mailto:jliu3@nshs.edu)
- **Jeffrey M. Lipton, MD, PhD**, Professor of Pediatrics, Chief, Division of Hematology/Oncology and Stem Cell Transplantation  
Telephone: 718-470-3460  
E-mail: [jlipton@lij.edu](mailto:jlipton@lij.edu)
- **Nancy Barbach, CSW**  
E-mail: [nbarbach@nshs.edu](mailto:nbarbach@nshs.edu)

#### Services Offered:

- ◆ Bone Marrow Failure Clinic offering comprehensive evaluation of adult and pediatric FA patients by an experienced team of multidisciplinary 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.

### Dana-Farber Cancer Institute

450 Brookline Avenue  
Boston, MA 02215

- **Eva C. Guinan, MD**  
Telephone: 617-632-4932 Fax: 617-632-3770  
E-mail: [Eva\\_Guinan@dfci.harvard.edu](mailto:Eva_Guinan@dfci.harvard.edu)

#### Services Offered:

- ◆ Comprehensive evaluation;
- ◆ Second opinions;
- ◆ Pre- and post-transplantation evaluation;
- ◆ Follow up care and planning.

## BONE MARROW FAILURE, cont'd

### Fred Hutchinson Cancer Research

#### Center

1100 Fairview Ave N  
Seattle, WA 98101  
[www.fhcrc.org](http://www.fhcrc.org)

### Seattle Children's Hospital

4800 Sand Point Way NE  
Seattle, WA 98105  
[www.seattlechildrens.org](http://www.seattlechildrens.org)

- **Akiko Shimamura, MD, PhD**, Director, Marrow Failure Program, Pediatric Hematology-Oncology, Seattle Children's Hospital, Associate Member, Fred Hutchinson Cancer Research Center Associate Professor of Pediatrics, University of Washington School of Medicine  
Telephone: 206-667-1127 Fax: 206-667-5255  
E-mail: [ashimamu@fhcrc.org](mailto:ashimamu@fhcrc.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  
E-mail: [hkiem@fhcrc.org](mailto:hkiem@fhcrc.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: 206-667-5594 Fax: 206-667-5899  
E-mail: [ksbaker@fhcrc.org](mailto:ksbaker@fhcrc.org)
- **Ann Woolfrey, MD**, Director, Unrelated Donor Program, Associate Member, Fred Hutchinson Cancer Research Center, Associate Professor of Pediatrics, University of Washington School of Medicine, Pediatric Hematopoietic Cell Transplant Program  
Telephone: 206-667-4453 Fax: 206-667-4310  
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- **Jennifer Adair, PhD**, Clinical Research Associate, Fred Hutchinson Cancer Research Center  
Telephone: 206-667-7110 Fax: 206-667-6124  
Email: [jadair@fhcrc.org](mailto:jadair@fhcrc.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
- **Jean Sanders, MD**, Member, Fred Hutchinson Cancer Research Center, Professor of Pediatrics, University of Washington School of Medicine.  
Telephone: 206-667-4348 Fax: 206-667-5899

#### Services Offered:

- ◆ Evaluation of new and previously diagnosed patients;
- ◆ Complementation group analysis (research basis);
- ◆ Personalized treatment regimens by specialists in hematology, bone marrow transplantation, cardiology, endocrinology, genetics, gastroenterology, nephrology, urology, orthopedics, 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;
- ◆ Collaborator, Hospital de Clinicas, University of Parana, Brazil (Carmem Bonfim, MD and Ricardo Pasquini, MD, PhD).



## BONE MARROW FAILURE, cont'd

### Hackensack University Medical Center

#### Tomorrow's Children Institute

30 Prospect Ave.  
Hackensack, NJ 07601  
[www.tcikids.com](http://www.tcikids.com)

- **Alfred P. Gillio, MD**, Director Bone Marrow Failure Clinic, Pediatric Hematology/Oncology  
Telephone: 201-996-5600 Fax: 201-996-0521  
E-mail: [agillio@humed.com](mailto:agillio@humed.com)
- **Barbara Adler-Brecher, MS**  
E-mail: [badler@humed.com](mailto:badler@humed.com)

#### 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  
Laboratory of Genome Maintenance  
1230 York Ave., Box 182  
New York, NY 10065

- **Agata Smogorzewska, MD, PhD**  
Telephone: 212-327-7850, or 8862 Fax: 212-327-8262  
E-mail: [asmogorzewska@rockefeller.edu](mailto:asmogorzewska@rockefeller.edu)  
<http://lab.rockefeller.edu/smogorzewska>
- **Arleen D. Auerbach, PhD**  
Telephone: 212-327-7533, or 8862 Fax: 212-327-8262  
E-mail: [auerbac@rockefeller.edu](mailto:auerbac@rockefeller.edu)
- **Erica Sanborn, MS, CGC**  
Telephone: 212-327-8613 Fax: 212-327-8262  
E-mail: [esanborn@rockefeller.edu](mailto:esanborn@rockefeller.edu)

#### Genetic Services on Research Protocol:

- ◆ International Fanconi Anemia Registry (IFAR);
- ◆ Derivation of lymphoblastoid cell line for complementation testing; maintenance of Fanconi anemia cell and DNA repositories;
- ◆ Mutation screening of probands for FA genes under investigation by the laboratory.
- ◆ Genetic counseling for individuals involved in the IFAR, and their family members.

#### Testing Services on Research Protocol:

- ◆ Mutation analysis (Research)
- ◆ *FANCD2* western blot (Research)

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## BONE MARROW FAILURE, cont'd

### International Fanconi Anemia Registry (IFAR), cont'd

#### Co-Principal Investigators for the IFAR:

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Memorial Sloan-Kettering Cancer Center, New York, NY  
Telephone: 212-639-6684 Fax: 212-717-3555  
E-mail: [bouladf@mskcc.org](mailto:bouladf@mskcc.org)
- **Stella Davies, MBBS, PhD, MRCP**  
Cincinnati Children's Hospital Medical Center, Cincinnati, OH  
Telephone: 513-636-1371 Fax: 513-636-3459  
E-mail: [stella.davies@cchmc.org](mailto:stella.davies@cchmc.org)
- **Margaret L. MacMillan, MD**  
University of Minnesota, Minneapolis, MN  
Telephone: 612-626-2778 Fax: 612-626-2815  
E-mail: [macmi002@umn.edu](mailto: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  
E-mail: [dik2002@med.cornell.edu](mailto:dik2002@med.cornell.edu)

### Memorial Sloan-Kettering Cancer Center

1275 York Ave.

New York, NY 10021

[www.mskcc.org](http://www.mskcc.org)

- **Farid Boulad, MD**, Medical Director, Pediatric Day Hospital, Pediatric Hematology and Bone Marrow Transplantation  
Telephone: 212-639-6684 Fax: 212-717-3447  
E-mail: [bouladf@mskcc.org](mailto:bouladf@mskcc.org)
- **Bhuvanesh Singh, MD, PhD**, Head and Neck Cancer  
Telephone: 212-639-2024  
E-mail: [singhb@mskcc.org](mailto:singhb@mskcc.org)
- **Mercedes Castiel, MD**, Gynecology  
Telephone: 212-639-5060  
E-mail: [castielm@mskcc.org](mailto:castielm@mskcc.org)
- **Julia A. Kearney, MD**, Psychiatry and Pediatrics  
Telephone: 646-888-0028  
E-mail: [Kearneyj@mskcc.org](mailto:Kearneyj@mskcc.org)

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## BONE MARROW FAILURE, cont'd

### Memorial Sloan-Kettering Cancer Center, cont'd

#### Services Offered:

- ◆ Comprehensive care and long-term follow-up of new and previously diagnosed patients, including: Hematopoietic Stem Cell Transplantation with related, unrelated, matched or mismatched donors, Head and Neck Cancer evaluation and treatment, Gynecological Cancer evaluation and treatment, and Endocrinology clinic;
- ◆ Direct collaboration with **Arleen Auerbach, PhD**, The Rockefeller University, for mutation screening, complementation group analysis, and somatic mosaicism studies;
- ◆ 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 Pl.

New York, NY 10029

- **Christopher Walsh, MD**, Associate Professor of Medicine  
Telephone: 212-241-3443  
E-mail: [christopher-e.walsh@msnyuhealth.org](mailto:christopher-e.walsh@msnyuhealth.org)
- **Luis Isola, MD**, Director, Stem Cell Transplantation Program
- **Anne Hurlet, 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.

## BONE MARROW FAILURE, cont'd

### National Cancer Institute

Clinical Genetics Branch, Division of Cancer Epidemiology and Genetics,  
National Institutes of Health

6120 Executive Blvd., Executive Plaza South, Room 7020  
Rockville, MD 20892-7231

[www.marrowsfailure.cancer.gov](http://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  
E-mail: [lisaleathwood@westat.com](mailto:lisaleathwood@westat.com)
- **Blanche P. Alter, MD, MPH, FAAP**  
Telephone: 301-402-9731 Fax: 301-212-5281  
E-mail: [alterb@mail.nih.gov](mailto:alterb@mail.nih.gov)
- **Neelam Giri, MD, FAAP**  
Telephone: 301-594-7642 Fax: 301-212-5281  
E-mail: [ginin@mail.nih.gov](mailto:ginin@mail.nih.gov)
- **Pamela Stratton, MD**, Chief, Gynecology Consult Service  
Telephone: 301-496-9079 Fax: 301-480-6703  
E-mail: [stratton@nih.gov](mailto:stratton@nih.gov)
- **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  
E-mail: [vanwaesc@nidcd.nih.gov](mailto:vanwaesc@nidcd.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, cont'd

### Oregon Health & Science University, Doernbecher Children's Hospital

3181 S.W. Sam Jackson Park Road  
Portland, OR 97239

- **Peter Kurre, MD**, Associate Professor, Division of Pediatric Hematology/Oncology  
Telephone: 503-494-1543 Fax: 503-494-0714  
E-mail: [kurrepe@ohsu.edu](mailto:kurrepe@ohsu.edu)
- **Evan Shereck, MD**, Assistant Professor of Pediatrics  
Telephone: 503-494-0829 Fax: 503-494-0714  
E-mail: [shereck@ohsu.edu](mailto:shereck@ohsu.edu)

#### Services Offered:

- ◆ Diagnostic evaluation and genetic counseling for FA and other marrow failure syndromes;
- ◆ 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, Lucille Packard Children's Hospital

Hematology Clinic  
770 Welch Road, Suite 261  
Palo Alto, CA 94304  
[www.lpch.org](http://www.lpch.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  
E-mail: [bglader@stanford.edu](mailto:bglader@stanford.edu)
- **Michael Jeng, MD**, Associate Professor, Pediatrics  
E-mail: [mjeng@stanford.edu](mailto:mjeng@stanford.edu)
- **Wendy Wong, MD**, Clinical Assistant Professor, Pediatrics  
E-mail: [wendy.wong@stanford.edu](mailto:wendy.wong@stanford.edu)
- **Judith Lea, RN, MSN, PNP**, Hematology Nurse Practitioner  
E-mail: [jlea@lpch.org](mailto:jlea@lpch.org)
- **Kirsten Mouradian, RN, MSN, FNP**, Hematology Nurse Practitioner  
E-mail: [kmouradian@lpch.org](mailto:kmouradian@lpch.org)

(Continued on the next page)

## BONE MARROW FAILURE, cont'd

### Stanford School of Medicine, Lucille Packard Children's Hospital, cont'd

Stem Cell Transplant Telephone: 650-725-9250

- **Kenneth Weinberg, MD**, Professor, Pediatrics  
E-mail: [kw1@stanford.edu](mailto:kw1@stanford.edu)
- **Rajni Agarwal, MD**, Assistant Professor, Pediatrics  
E-Mail: [rajnia@stanford.edu](mailto:rajnia@stanford.edu)
- **Sandhya Kharbanda, MD**, Assistant Professor of Pediatrics  
E-mail: [ksandhya@stanford.edu](mailto:ksandhya@stanford.edu)
- **Karen Kristovich, RN, MSN, PNP**, Stem Cell Transplant Nurse Practitioner  
E-mail: [kkristovich@lpch.org](mailto:kkristovich@lpch.org)
- **Tracey Stoll, RN**, Related Donor Stem Cell Transplant Coordinator  
E-mail: [tstoll@lpch.org](mailto:tstoll@lpch.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.

### University of Minnesota, Fanconi Anemia Comprehensive Care Program, University of Minnesota Medical Center and Amplatz Children's Hospital

MMC 366, University of Minnesota

420 Delaware St., S.E.

Minneapolis, MN 55455

Telephone: 612-273-2800

[www.bmt.umn.edu/disease/fanconi-anemia](http://www.bmt.umn.edu/disease/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  
E-mail: [wagne002@umn.edu](mailto: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  
E-mail: [macmi002@umn.edu](mailto: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](mailto:tolar003@umn.edu)
- **Anna Petryk, MD**, Pediatric Endocrinology  
Telephone: 612-624-5409 Fax: 612-626-5262  
E-mail: [petry005@umn.edu](mailto:petry005@umn.edu)

(Continued on the next page)

## BONE MARROW FAILURE, cont'd

### University of Minnesota, Fanconi Anemia Comprehensive Care Program, cont'd

- **Sarah Jane Schwarzenberg, MD**, Pediatric Gastroenterology  
Telephone: 612-624-1133 Fax: 612-626-0639  
E-mail: [schwa005@umn.edu](mailto:schwa005@umn.edu)
- **Frank Ondrey, MD, PhD, FACS**, Otolaryngology  
Telephone: 612-624-5900  
E-mail: [ondre002@umn.edu](mailto:ondre002@umn.edu)
- **Rahel G. Ghebre, MD**, Gynecologic Oncology  
Telephone: 612-626-2613 Fax: 612-626-0665  
E-mail: [ghebr004@umn.edu](mailto:ghebr004@umn.edu)
- **Ann E. Van Heest, MD**, Dept. of Orthopaedic Surgery  
Telephone: 612-273-8086 Fax: 612-273-7959  
E-mail: [Vanhe003@umn.edu](mailto:Vanhe003@umn.edu)
- **Jo-Anne H. Young, MD**, Infectious Disease  
Telephone: 612-624-9996 Fax: 612-625-4410  
E-mail: [Vanbu004@umn.edu](mailto:Vanbu004@umn.edu)
- **Pat Fidler, RN**, Nurse Coordinator  
Telephone: 612-273-8480 Fax: 612-273-2919  
E-mail: [pfidler1@fairview.org](mailto:pfidler1@fairview.org)
- **Heather Zierhut, MS, CGC**, Certified Genetic Counselor  
Telephone: 612-626-6743 Fax: 612-273-2919  
E-mail: [hzierhu1@fairview.org](mailto:hzierhu1@fairview.org)

#### 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 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);

(Continued on the next page)

## BONE MARROW FAILURE, cont'd

### University of Minnesota, Fanconi Anemia Comprehensive Care Program, cont'd

- ◆ 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.

### The University of Texas Southwestern Medical Center Pediatric Bone Marrow Failure Program Children's Medical Center Dallas

Center for Cancer and Blood Disorders  
1935 Medical District Drive  
Dallas, TX 75235

#### To Contact us:

Telephone: 214-456-2382 or 214-456-6102

Email: [BoneMarrowFailure@UTSouthwestern.edu](mailto:BoneMarrowFailure@UTSouthwestern.edu)

#### Nurse Coordinator:

- **Deborah J. Boger, MSN, RN, CPNP** Bone Marrow Failure Nurse Practitioner  
Telephone: 214-456-6102 Fax: 214-456-8469

#### Medical Staff:

- **Zora R. Rogers, MD**, Professor of Pediatrics, Hematology-Oncology  
Clinical Director, Bone Marrow Failure Program  
E-mail: [zora.rogers@utsouthwestern.edu](mailto:zora.rogers@utsouthwestern.edu)
- **Andrew Koh, MD**, Assistant Professor of Pediatrics, Hematology-Oncology  
Director, Stem Cell Transplant Program

#### 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, nephrology, hand and orthopedic surgery interested in the unique needs of persons with Fanconi anemia; and
- ◆ Psychology, Social Work, Physical and Occupational Therapy services.



# BONE MARROW DONOR REGISTRIES

## **DKMS Americas**

33 East 33rd Street, Suite 501  
New York, NY 10016  
www.dkmsamericas.org  
Telephone: 1-866-340-DKMS (3567)  
E-mail: [info@dkmsamericas.org](mailto:info@dkmsamericas.org)

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.

### **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®**

3001 Broadway Street NE, Suite 100  
Minneapolis, MN 55413-1753  
[www.marrow.org](http://www.marrow.org)  
Telephone: 1-888-999-6743. Outside of the US: 612-632-3410  
E-mail: [patientinfo@nmdp.org](mailto:patientinfo@nmdp.org)

The National Marrow Donor Program (NMDP) is the global leader in providing marrow and umbilical cord blood transplants to patients with leukemia, lymphoma and other diseases. The nonprofit organization matches patients with donors, educates health care professionals and conducts research so more lives can be saved. The NMDP also operates **Be The Match®**, which provides support for patients and enlists others in the community to join the Be The Match Registry®—the world's largest listing of potential marrow donors and donated cord blood units.

### **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](http://www.cordblood.com)

Telephone: 1-888-932-6568

Cord Blood Registry® (CBR) is the world's largest and most experienced family cord blood & 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 5 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.

For more information on this program, please contact Cord Blood Registry at 1-888-932-6568 or visit [www.cordblood.com](http://www.cordblood.com).

## ENDOCRINOLOGY

### **Cincinnati Children's Hospital Medical Center,** **The Fanconi Anemia Comprehensive Care Center**

3333 Burnet Ave.

Cincinnati, OH 45229

- **Susan R. Rose, MD, MEd**, Professor of Pediatrics, Pediatric Endocrinology  
Telephone: 513-636-4744  
E-mail: [susan.rose@cchmc.org](mailto:susan.rose@cchmc.org)
- **Meilan Rutter, MD**, Associate Professor of Pediatrics, Division of Endocrinology  
Telephone: 513-636-4744  
E-mail: [meilan.rutter@cchmc.org](mailto:meilan.rutter@cchmc.org)

## ENDOCRINOLOGY, cont'd

**University of Minnesota, Fanconi Anemia Comprehensive Care Program,**  
**University of Minnesota Medical Center and Amplatz Children's Hospital**

MMC 366, University of Minnesota  
420 Delaware St., S.E.  
Minneapolis, MN 55455

- **Anna Petryk, MD**, Pediatric Endocrinology  
Telephone: 612-624-5409 Fax: 612-626-5262  
E-mail: [petry005@umn.edu](mailto:petry005@umn.edu)

## GASTROENTEROLOGY

**Cincinnati Children's Hospital Medical Center,**  
**The Fanconi Anemia Comprehensive Care Center**

3333 Burnet Ave.  
Cincinnati, OH 45229

- **Nada Yazigi, MD**, Assistant Professor of Pediatrics, Pediatric Gastroenterology  
Telephone: 513-636-4415 Fax: 513-636-7805  
E-mail: [nada.yazigi@cchmc.org](mailto:nada.yazigi@cchmc.org)

**University of Minnesota, Fanconi Anemia Comprehensive Care Program,**  
**University of Minnesota Medical Center and Amplatz Children's Hospital**

MMC 366, University of Minnesota  
420 Delaware St., S.E.  
Minneapolis, MN 55455

- **Sarah Jane Schwarzenberg, MD**, Director, Pediatric Gastroenterology, Hepatology and Nutrition  
Telephone: 612-624-1133 Fax: 612-626-0639  
E-mail: [schw005@umn.edu](mailto:schw005@umn.edu)

## GENETIC COUNSELING

### **Rockefeller University**

1230 York Avenue Box 182  
New York, NY 10065

- **Erica Sanborn, MS, CGC**, Certified Genetic Counselor\*  
Telephone: 212-327-8613 Fax: 212-327-8262  
E-mail: [esanborn@rockefeller.edu](mailto:esanborn@rockefeller.edu)

\*Genetic counseling provided for IFAR participants and their family members.  
Please see pages 15-16 for more information about the IFAR.

### **University of Minnesota, Fanconi Anemia Comprehensive Care Program, University of Minnesota Medical Center and Amplatz Children's Hospital**

MMC 366, University of Minnesota  
420 Delaware St., S.E.  
Minneapolis, MN 55455  
Telephone 612-273-2800  
[www.bmt.umn.edu/disease/fanconi-anemia](http://www.bmt.umn.edu/disease/fanconi-anemia)

- **Heather Zierhut, MS, CGC**, Certified Genetic Counselor  
Telephone: 612-626-6743 Fax: 612-273-2919  
E-mail: [hzierhu1@fairview.org](mailto:hzierhu1@fairview.org)

## GYNECOLOGY

### **Cincinnati Children's Hospital Medical Center, The Fanconi Anemia Comprehensive Care Center**

3333 Burnet Ave.  
Cincinnati, OH 45229

- **Jill Huppert, MD, MPH**, Pediatric and Adolescent Gynecology  
Telephone: 513-636-7042 Fax: 513-636-8844  
E-mail: [jill.huppert@cchmc.org](mailto:jill.huppert@cchmc.org)

### 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  
E-mail: [Stratton@nih.gov](mailto:Stratton@nih.gov)

### Memorial Sloan-Kettering Cancer Center

1275 York Ave.  
New York, NY 10021

- **Mercedes Castiel, MD**, Gynecology  
Telephone: 212-639-5060  
E-mail: [castielm@mskcc.org](mailto:castielm@mskcc.org)

### University of Minnesota, Fanconi Anemia Comprehensive Care Program, University of Minnesota Medical Center, Amplatz Children's Hospital, Fairview

MMC 366, University of Minnesota  
420 Delaware St., S.E.  
Minneapolis, MN 55455

- **Rahel G. Ghebre, MD**, Gynecologic Oncology  
Telephone: 612-626-2613 Fax: 612-626-0665  
E-mail: [ghebr004@umn.edu](mailto:ghebr004@umn.edu)

## 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  
E-mail: *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,** **The Fanconi Anemia Comprehensive Care Center**

3333 Burnet Ave.

Cincinnati, OH 45229

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

### **Shriners Hospital for Children**

3551 North Broad St.

Philadelphia, PA 19140

- **Scott Kozin, MD**, Professor, Orthopedic Surgery, Temple University, Hand & Upper Extremity Surgeon  
Telephone: (215) 430-4034  
E-mail: *skozin@shrinenet.org*
- **Linda Filipone**, Nurse Coordinator  
Telephone: (215) 430-4074  
E-mail: *lfilipone@shrinenet.org*

*(Continued on the next page)*

## HAND SURGEONS, cont'd

### Shriners Hospital for Children, cont'd

- **Maureen Fulcher**, Nurse Assistant  
Telephone: (215) 430-4204  
E-mail: [mfulcher@shrinenet.org](mailto: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 Ave., Suite 205  
Needham, MA 02494  
[www.bostonsight.org](http://www.bostonsight.org)

- **Nancy Lemist**, New Patient Affairs Coordinator  
Telephone: 781-726-7501 Fax: 781-726-7310  
E-mail: [nlemist@bostonsight.org](mailto:nlemist@bostonsight.org)

Boston Foundation for Sight is a non-profit organization dedicated to helping patients whose eye functions are impaired by damaged/diseased corneas.

#### Services Offered:

Custom fitting of the Boston Ocular Surface Prosthesis. This device acts like a corneal liquid bandage, able to provide significant relief to those patients who are unresponsive to low risk treatments for severe dry eyes due to graft versus host disease, etc. This service is offered to all who may benefit, regardless of their ability to pay.

# OTOLARYNGOLOGY (Ear, Nose, and Throat) and HEAD AND NECK CANCER

## Cincinnati Children's Hospital Medical Center, The Fanconi Anemia Comprehensive Care Center

3333 Burnet Ave.

Cincinnati, OH 45229

- **Michael Rutter, MD**, Professor of Pediatrics, Division of Otolaryngology  
Telephone: 513-636-4881 Fax: 513-636-8133  
E-mail: [mike.rutter@cchmc.org](mailto: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  
E-mail: [dik2002@med.cornell.edu](mailto:dik2002@med.cornell.edu)

**Clinical Interests:** Head & 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  
E-mail: [jcalifa@jhmi.edu](mailto: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 Ave.  
New York, NY 10021

- **Bhuvanesh Singh, MD, PhD**, Head and Neck Cancer  
Telephone: 212-639-2024  
E-mail: [singhb@mskcc.org](mailto: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, NIH, Associate Professor, Department of Otolaryngology (Ears, Nose, Throat), Head and Neck Surgery, Georgetown University Hospital  
Telephone: 301-496-5369 Fax: 301-402-0409  
E-mail: [kimj@nidcd.nih.gov](mailto: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  
E-mail: [vanwaesc@nidcd.nih.gov](mailto:vanwaesc@nidcd.nih.gov)

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

## University of Chicago Medical Center

5841 S. Maryland Avenue  
Chicago, IL 60634

- **Ezra Cohen, MD**, Associate Professor of Medicine  
Telephone: 773-702-4137 Fax: 773-702-2835  
E-mail: [ecohen@medicine.bsd.uchicago.edu](mailto:ecohen@medicine.bsd.uchicago.edu)

**Clinical Interests:** Head and Neck Cancer, Lung Cancer, Esophageal Cancer

- **Everett Vokes, MD**, John E. Ulmann Professor of Medicine and Radiation and Cellular Oncology and Chairman, Department of Medicine  
Telephone: 773-702-9306 Fax: 773-702-4427  
E-mail: [evokes@medicine.bsd.uchicago.edu](mailto:evokes@medicine.bsd.uchicago.edu)

**Clinical Interests:** Hematology, Oncology, Head and Neck Cancer, Lung Cancer, Esophageal Cancer

## University of Cincinnati, College of Medicine

Department of Otolaryngology  
234 Albert Sabin Way  
ML 0528  
Cincinnati, OH 45267

- **Keith A. Casper, MD**, Assistant Professor  
Telephone: 513-558-1890 Fax: 513-558-4477  
E-mail: [Keith.casper@uc.edu](mailto: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 Amplatz Children's Hospital

MMC 396, University of Minnesota  
420 Delaware St., SE  
Minneapolis, MN 55455

- **Frank Ondrey, MD, PhD, FACS**, Associate Professor of Otolaryngology, Director, Molecular Oncology Program  
Telephone: 612-624-5900  
E-mail: [ondre002@umn.edu](mailto:ondre002@umn.edu)

**Clinical Interests:** Head and Neck Cancer, Precancerous Mouth and Throat Lesions, Comprehensive General Otolaryngology, and Facial Trauma

## University of Pittsburgh School of Medicine Eye & Ear Institute

Suite 300

203 Lothrop Street

Pittsburgh, PA 15213

- **Jennifer Rubin Grandis, MD, FACS**, Professor  
Telephone: 412-647-2100  
E-mail: [jgrandis@pitt.edu](mailto:jgrandis@pitt.edu)

**Specialty:** Otolaryngology

**Sub Specialty:** Head & Neck Surgery

## University of Texas MD Anderson Cancer Center

1515 Holcombe Blvd., Unit 441

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 & Neck Cancer, Salivary Carcinoma, and Thyroid Cancer, Human Papillomavirus, and Sarcomas of the Head and Neck

**Services Offered:** Multidisciplinary evaluation and treatment of head and neck tumors.

# PRE-IMPLANTATION GENETIC DIAGNOSIS

## The Genesis Genetics Institute, Genomic Technology Center

Genomics Center at Samaritan - A1100

5555 Conner

Detroit, MI 48213

[www.genesisgenetics.org](http://www.genesisgenetics.org)

- **Mark Hughes, MD, PhD**  
Telephone: 313-579-9650 Fax: 313-544-4006  
E-mail: [pgd@genesisgenetics.org](mailto:pgd@genesisgenetics.org)
- **Shannon DeWall, MS, CGC**, Certified Genetic Counselor  
Telephone: 313-579-9650 Fax: 313-544-4006  
E-mail: [counselor@genesisgenetics.org](mailto:counselor@genesisgenetics.org)
- **Lauren Isley, MS**, Genetic Counselor  
Telephone: 313-579-9650 Fax: 313-544-4006

### Services Offered:

- ◆ Pre-pregnancy/pre-implantation diagnosis of FANC A, C, G. Helping a couple begin a pregnancy knowing their baby will not have Fanconi anemia;
- ◆ Extensive experience in Fanconi 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-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 anywhere for these PGD services. Our clinic collaborates with the leading molecular biologists in Fanconi research, with over 230 *in vitro* fertilization programs, and with internationally respected Fanconi transplantation experts.

## The Reproductive Genetics Institute

2825 N Halsted St.

Chicago, IL 60657

Telephone: 773-472-4900 Fax: 773-871-5221

[www.reproductivegenetics.com](http://www.reproductivegenetics.com)

E-mail: [rgiworld@gmail.com](mailto:rgiworld@gmail.com)

- **Christina Lavin, MS, CGC**
- **Andria Besser, MS, CGC**
- **Anna Cisler, MS, CGC**

### Services Offered:

- ◆ Pre-implantation genetic diagnosis for known Fanconi mutations with or without HLA matching for sibling bone marrow donation.

Watch for the ***FA Courier***, an annual publication by the Fanconi Anemia Research Fund.

The ***FA Courier*** offers a summary of research studies and clinical trials available for patients with Fanconi anemia.