

# 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

44 Binney St.  
Boston, MA 02115

<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 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;
- ◆ 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)
- **Roger Cornwall, MD**, Assistant Professor of Pediatrics, Division of Orthopaedics (Hand Surgery)  
Telephone: 513-636-7319 Fax: 513-636-3928  
E-mail: [roger.cornwall@cchmc.org](mailto:roger.cornwall@cchmc.org)

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## BONE MARROW FAILURE, cont'd

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

- **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)
- **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)
- **Parinda Mehta, MD**, Assistant 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
- **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)
- **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)

#### 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;
- ◆ Gene therapy, pharmacological, and other clinical trials (such as with cytokines, novel androgens, and Etanercept);
- ◆ Fanconi anemia repository for samples and data;
- ◆ Expertise in matched sibling donor and unrelated donor transplantation for Fanconi anemia;
- ◆ Fanconi anemia complementation 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**, Director, Pediatric Hematology/Hematopoietic Cell Transplantation
- **Debbie Hitt, RN**, Nurse-Coordinator, Pediatric Hematology/Hematopoietic Cell Transplantation
- **Nadia Ewing, MD**, Director, Pediatric Hematology
- **Anna Pawlowska, MD**, Pediatric Hematology/Hematopoietic Cell Transplantation
- **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.

### Dana-Farber Cancer Institute

44 Binney St.

Boston, MA 02115

- **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**, 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)
- **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  
E-mail: [awoolfre@fhcrc.org](mailto:awoolfre@fhcrc.org)
- **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, Medical Director, Pediatric Hematopoietic Cell Transplant Program  
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.

### 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)

#### 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.

## BONE MARROW FAILURE, cont'd

### 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.

### 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: 301-881-1463  
E-mail: [lisaleathwood@westat.com](mailto:lisaleathwood@westat.com)
- **Blanche P. Alter, MD, MPH, FAAP**  
Telephone: 301-402-9731 Fax: 301-496-1854  
E-mail: [alterb@mail.nih.gov](mailto:alterb@mail.nih.gov)
- **Neelam Giri, MD, FAAP**  
Telephone: 301-594-7642 Fax: 301-496-1854  
E-mail: [girin@mail.nih.gov](mailto:girin@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)

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

### **National Cancer Institute, cont'd**

#### **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.

### **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)

#### **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.

### **International Fanconi Anemia Registry (IFAR)**

#### **The Rockefeller University**

Laboratory of Genome Maintenance  
1230 York Ave., Box 182  
New York, NY 10065- 6399

- **Arleen D. Auerbach, PhD**  
Telephone: 212-327-7533, or 8862 Fax: 212-327-8262  
E-mail: [auerbac@rockefeller.edu](mailto:auerbac@rockefeller.edu)  
<http://www.rockefeller.edu/labheads/auerbach/>
- **Agata Smogorzewska, MD, PhD**  
Telephone: 212-327-7850, or 8862 Fax: 212-327-8262  
E-mail: [asmogorzewska@rockefeller.edu](mailto:asmogorzewska@rockefeller.edu)  
<http://www.rockefeller.edu/labheads/smogorzewska/>

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## BONE MARROW FAILURE, cont'd

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

#### Services Offered:

#### 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.

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

### Schneider Children's Hospital, Albert Einstein School of Medicine

#### 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*
- **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*
- **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*

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## BONE MARROW FAILURE, cont'd

### Schneider Children's Hospital, Albert Einstein School of Medicine, cont'd

#### 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.

### 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)

#### 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.

## BONE MARROW FAILURE, 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

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)
- **Anna Petryk, MD**, Pediatric Endocrinology  
Telephone: 612-624-5409 Fax: 612-626-5262  
E-mail: [petry005@umn.edu](mailto:petry005@umn.edu)
- **Sarah Jane Schwarzenberg, MD**, Pediatric Gastroenterology  
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Telephone: 612-626-2961 Fax: 612-626-1434  
E-Mail: [baker084@umn.edu](mailto:baker084@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  
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- **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)

(Continued on the next page)

## BONE MARROW FAILURE, cont'd

### University of Minnesota Medical Center and Amplatz Children's Hospital, cont'd

#### 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);
- ◆ 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.

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

**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*

**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*
- **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
- ◆ 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](http://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.

As the world's largest bone marrow donor center, DKMS:

- ◆ Organizes thousands of Bone Marrow Donor Drives across the U.S. to recruit healthy, committed donors; We do not make the testing fee mandatory, but rely on donations to support our life-saving work;
- ◆ Provides patients with access to more than 2 million registered donors; more than 25% of all transplants are provided by DKMS;
- ◆ 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;
- ◆ Coordinates all transports of bone marrow and blood stem cells from Germany to USA.

## **National Marrow Donor Program® Be The Match Registry<sup>SM</sup>**

3001 Broadway Street NE, Suite 100

Minneapolis, MN 55413-1753

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

Telephone: 1-888-999-6743. Outside of the US: 612-632-3410

Email: [patientinfo@nmdp.org](mailto:patientinfo@nmdp.org)

The National Marrow Donor Program (NMDP) has been helping people who need a potentially life-saving marrow or cord blood transplant for more than 20 years. Be The Match Registry<sup>SM</sup> is the new name of the NMDP's registry

### **Services Offered:**

- ◆ We connect patients, doctors, donors and researchers to the resources they need to help more people live longer and healthier lives;
- ◆ Assist patients and families in Donor Drives with event planning and coordination, media support, and fundraising.;
- ◆ The NMDP's Office of Patient Advocacy (OPA) offers resources and services to help patients and their families from diagnosis through survivorship. All OPA materials and services are free and confidential.

# CORD BLOOD REGISTRIES

## **Cord Blood Registry®**

Designated Transplant Program (DTP)

Cord Blood Registry

1200 Bayhill Drive, 3rd Floor

San Bruno, CA 94066

*www.cordblood.com*

Telephone: 1-888-Cord-Blood

### **Services Offered:**

- ◆ Cord Blood Registry® (CBR) is the world's largest and most experienced family cord blood stem cell bank. As a public service, CBR provides the Designated Transplant Program (DTP) to families wishing to store their newborn's umbilical cord blood stem cells for a family member diagnosed with a life-threatening disease treatable by stem cell transplantation, including Fanconi anemia. CBR provides the collection kit, processing and storage of the newborn's umbilical cord blood without any cost to families qualifying for the DTP.
- ◆ For more information on the DTP, including the qualification criteria and the application process, please contact Cord Blood Registry at 1-888-Cord-Blood or visit *www.cordblood.com*.

## **National Marrow Donor Program® (NMDP) Related Donor Cord Blood Program**

3001 Broadway St. NE, Suite 100

Minneapolis, MN 55413

*www.marrows.org*

Telephone: 1-888-999-6743. Outside of the USA: 612-632-3410

Email: *patientinfo@nmdp.org*

### **Services Offered:**

- ◆ For families with a first-degree relative diagnosed with Fanconi anemia or with an other medical condition that might benefit from a cord blood transplant in the USA;
- ◆ No charge to the family when a new baby is born into an eligible family, to have that baby's umbilical cord blood collected and stored until it can be used for a transplant;
- ◆ The NMDP's Office of Patient Advocacy patient services coordinators can answer questions about the Related Donor Cord Blood Program, eligibility guidelines, insurance and how to contact a participating cord blood bank;
- ◆ Note: the cord blood bank determines final eligibility for this program.

## 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)

**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: [schwa005@umn.edu](mailto:schwa005@umn.edu)

## GENETIC COUNSELING

### 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)

## GYNECOLOGY, cont'd

### **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*

### **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*

## 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  
Telepone: 612-596-6100

#### **Services Offered:**

- ◆ Hand and upper extremity surgery in the pediatric population

## HAND SURGEONS, cont'd

### 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: 513-636-7319 Fax: 513-636-3928  
E-mail: [roger.cornwall@cchmc.org](mailto: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](mailto:skozin@shrinenet.org)
- **Linda Filipone**, Nurse Coordinator  
Telephone: (215) 430-4074  
E-mail: [lfilipone@shrinenet.org](mailto:lfilipone@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)

- **Brenda Diaz**, New Patient Coordinator  
Telephone: 781-726-7337, ext. 101 Fax: 781-726-7310  
E-mail: [bdiaz@bostonsight.org](mailto:bdiaz@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**, 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)

## 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.

## OTOLARYNGOLOGY and HEAD AND NECK CANCER, cont'd

### National Institutes of Health

NIDCD/NIH

10 Center Drive, Building 10  
Bethesda, MD 20892

- **H. Jeffrey Kim, MD**, Associate Professor, Department of Otolaryngology (Ears, Nose, Throat), Head and Neck Surgery  
Telephone: 301-496-5369  
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:** Associate investigator on Dr. Blanche Alter's protocol, for diagnosis of head and neck mucosal lesions and cancers for participating patients.

### 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

## **OTOLARYNGOLOGY and HEAD AND NECK CANCER, cont'd**

### **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*
- **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*

**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*

**Specialty:** Otolaryngology

**Sub Specialty:** Head & Neck Surgery

## OTOLARYNGOLOGY and HEAD AND NECK CANCER, cont'd

### University of Texas MD Anderson Cancer Center

1515 Holcombe Blvd., Unit 441  
Houston, TX 77030

- **Erich Madison Sturgis, MD, MPH, FACS**, Associate Professor of Surgery, Associate 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: 313-544-4006 Fax: 313-544-4006  
E-mail: [pgd@genesisgenetics.org](mailto:pgd@genesisgenetics.org)
- **Shannon Wiltse, MS, CGC**, Certified Genetic Counselor  
Telephone: 313-544-4006 Fax: 313-544-4006  
E-mail: [counselor@genesisgenetics.org](mailto:counselor@genesisgenetics.org)

#### **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.

## PRE-IMPLANTATION GENETIC DIAGNOSIS, cont'd

### **The Reproductive Genetics Institute**

2825 N Halsted St.

Chicago, IL 60657

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

*www.reproductivegenetics.com*

E-mail: *rgiworld@gmail.com*

- Dana Pauling, MS, CGC
- Christina Lavin, MS, CGC
- Andria Besser, MS
- Anna Cisler, MS

### **Services Offered:**

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