

US Fanconi Anemia Treatment Resource Guide

Editors' Note and Disclaimer: The resources provided in this guide are not meant to be inclusive. The reader should not consider the resources here to be endorsements by the Fanconi Anemia Research Fund, Inc.

BONE MARROW FAILURE:

The Children's Hospital, Boston, The Fanconi Anemia and Bone Marrow Failure Multidisciplinary Clinic

300 Longwood Ave.

Boston, MA 02115

www.childrenshospital.org/fa-bmf

Program Coordinator:

- Telephone: 617-919-2697 Fax: 617-730-0641
E-mail: FA-BMF@childrens.harvard.edu

Co-Directors:

- **David A. Williams, MD**
Telephone: 617-919-2697
E-mail: DAWilliams@childrens.harvard.edu
- **Colin Sieff, MBBCh**
Telephone: 617-355-7700
E-mail: Colin.Sieff@childrens.harvard.edu

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.

Diagnostic Services include DEB testing and retrovirus complementation analysis coordinated with Dr. Alan D'Andrea and Lisa Moreau at The Diagnostic Center for Fanconi Anemia at Dana-Farber Cancer Institute (see separate listing).

We also facilitate 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. The current available testing for FANCA, FANCC, and FANCG are listed at www.GeneTests.org/. **Genetic Counselor:** Ann E Reinhard, MS, CGC
E-mail: ann.reinhard@childrens.harvard.edu / phone: (617) 355-4907 fax: (617) 730-0466

Below is a direct link for the lab and contact information for referral:

http://www.genetests.org/servlet/access?prg=j&db=genestar&site=gt&fcn=z&fcn2=oo&id=8888892&qry=1179&res=&key=sISF3afRvFJBB&show_flag=c

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The Children's Hospital, Boston, cont'd:

We can also refer families for pre-implantation genetic diagnosis services at two sites in Boston if we find disease-causing mutations.

Specialists:

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

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

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

3333 Burnet Ave.

Cincinnati, OH 45229

- **Stella Davies, MB BS, PhD, MRCP**, Jacob G. Schmidlapp Endowed Chair and Professor of Pediatrics, University of Cincinnati College of Medicine, Director, Bone Marrow Transplantation and Immune Deficiency Program
Telephone: (513) 636-1371 Fax: (513) 636-3549
E-mail: 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
- **Richard Harris, MD**, Professor of Pediatrics, Director of the Bone Marrow Failure Program, Bone Marrow Transplantation and Immune Deficiency Program
Telephone: (513) 636-8610 Fax: (513) 636-7951
E-mail: 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
- **Parinda Mehta, MD**, Assistant Professor of Pediatrics, Bone Marrow Transplantation and Immune Deficiency Program
Telephone: (513) 636-5917 Fax: (513) 636-3549
E-mail: parinda.mehta@cchmc.org
- **Robin Mueller, RN**, Nurse Coordinator, Fanconi Anemia Comprehensive Care Center
Telephone: (513) 636-3218 Fax: (513) 636-7951
E-mail: robin.mueller@cchmc.org
- **Susan R. Rose, MD, MEd**, Professor of Pediatrics, Pediatric Endocrinology
Telephone: (513) 636-4744
E-mail: susan.rose@cchmc.org
- **Meilan Rutter, MD**, Associate Professor of Pediatrics, Division of Endocrinology
Telephone: (513) 636-4744
E-mail: 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
- **Nada Yazigi, MD**, Assistant Professor of Pediatrics, Pediatric Gastroenterology
Telephone: (513) 636-4415 Fax: (513) 636-7805
E-mail: 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**).

City Of Hope

1500 E. Duarte Rd.

Duarte, CA 91010

Telephone: (626) 301-8442

E-mail: 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
- **Ellen Bolotin, MD, PhD**, Pediatric Hematology/Hematopoietic Cell Transplantation
- **Anna Pawlowska, MD**, Pediatric Hematology/Hematopoietic Cell Transplantation
- **Marilyn Slovak, 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;
- ◆ Provide 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.

The Comprehensive Center for Fanconi Anemia

Dana-Farber Cancer Institute

44 Binney St.

Boston, MA 02115

<http://research2.dfci.harvard.edu/FANC/testing.html>

- **Alan D'Andrea, MD**, Chief, Division of Genomic Stability and DNA Repair, The Comprehensive Center for Fanconi Anemia
Telephone: (617) 632-2112
- **Lisa A. Moreau, MS, CLSpCG**, Supervisor of Clinical Laboratory
Laboratory: (617) 632-6302
Office: (617) 632-5792
Fax: (617) 632-5757
E-mail: Lisa_Moreau@dfci.harvard.edu

Services Offered:

- ◆ Diagnosis of new FA patients through Clinical Laboratory Improvement Act (CLIA) certified diepoxybutane (DEB) test;
- ◆ Complementation analysis via retrovirus gene transfer;
- ◆ Fundamental research in DNA repair pathways;
- ◆ Coordination with The Fanconi Anemia and Bone Marrow Failure Multidisciplinary Clinic at The Children's Hospital of Boston, MA.

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*

Services Offered:

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

Fred Hutchinson Cancer Research Center

1100 Fairview Ave N
Seattle, WA 98101

Seattle Children's Hospital

4800 Sand Point Way NE
Seattle, WA 98105

- **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*
- **Monica Thakar, MD**, Research Associate, Fred Hutchinson Cancer Research Center Acting Instructor of Pediatrics, University of Washington School of Medicine, Pediatric Hematopoietic Cell Transplant Program
Telephone: (206) 667-5946 Fax: (206) 667-6124
E-mail: *msthakar@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*
- **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: *a woolfre@fhcrc.org*

(Continued on the next page)

Fred Hutchinson Cancer Research Center/Seattle Children's Hospital, cont'd

- **Jennifer Adair, PhD**, Clinical Research Associate, Fred Hutchinson Cancer Research Center
Telephone: (206)667-7110 Fax: (206) 667-6124
Email: 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).

Hackensack University Medical Center

Tomorrow's Children Institute

30 Prospect Ave.

Hackensack, NJ 07601

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
- **Barbara Adler-Brecher, MS**
E-mail: 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

- **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
- **Bhuvanesh Singh, MD, PhD**, Head and Neck Cancer
Telephone: (212) 639-2024
E-mail: singhb@mskcc.org
- **Mercedes Castiel, MD**, Gynecology
Telephone: (212) 639-5060
E-mail: castielm@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.

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
- **Luis Isola, MD**, Director, Stem Cell Transplantation Program
- **Anne Hurllet, 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

- **Lisa Leathwood, RN, BSN**, Research Nurse and Study Coordinator
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- **Blanche P. Alter, MD, MPH, FAAP**
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E-mail: alterb@mail.nih.gov
- **Neelam Giri, MD, FAAP**
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E-mail: ginin@mail.nih.gov
- **Pamela Stratton, MD**, Chief, Gynecology Consult Service
Telephone: (301) 496-9079 Fax: (301) 480-6703
E-mail: 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

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

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
<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
<http://www.rockefeller.edu/labheads/smogorzewska/>

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

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Schneider Children's Hospital, Albert Einstein School of Medicine Bone Marrow Failure Program, cont'd

- **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

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

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
- **Michael Jeng, MD**, Associate Professor, Pediatrics
E-mail: mjeng@stanford.edu
- **Wendy Wong, MD**, Clinical Assistant Professor, Pediatrics
E-mail: wendy.wong@stanford.edu
- **Judith Lea, RN, MSN, PNP**, Hematology Nurse Practitioner
E-mail: jlea@lpch.org
- **Kirsten Mouradian, RN, MSN, FNP**, Hematology Nurse Practitioner
E-mail: kmouradian@lpch.org

Stem Cell Transplant Telephone: (650) 725-9250

- **Kenneth Weinberg, MD**, Professor, Pediatrics
E-mail: kw1@stanford.edu
- **Rajni Agarwal, MD**, Assistant Professor, Pediatrics
E-Mail: rajnia@stanford.edu
- **Sandhya Kharbanda, MD**, Assistant Professor of Pediatrics
E-mail: ksandhya@stanford.edu
- **Karen Kristovich, RN, MSN, PNP**, Stem Cell Transplant Nurse Practitioner
E-mail: kkristovich@lpch.org
- **Tracey Stoll, RN**, Related Donor Stem Cell Transplant Coordinator
E-mail: 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, Amplatz Children's Hospital, Fairview

MMC 366, University of Minnesota

420 Delaware St., S.E.

Minneapolis, MN 55455

Telephone (612) 273-2800

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
- **Margaret L. MacMillan, MD**, Fanconi Anemia Comprehensive Care Program Leader, Assistant Professor, Department of Pediatrics, Division of Blood and Marrow Transplantation
Telephone: (612) 626-2778 Fax: (612) 626-2815
E-mail: macmi002@umn.edu
- **Anna Petryk, MD**, Pediatric Endocrinology
Telephone: (612) 624-5409 Fax: (612) 626-5262
E-mail: petry005@umn.edu
- **Sarah Jane Schwarzenberg, MD**, Pediatric Gastroenterology
Telephone: (612) 624-1133 Fax: (612) 626-0639
E-mail: schwa005@umn.edu
- **Daniel Mulrooney, MD, MS**, Stem Cell Transplantation/Late Effects Clinic
Telephone: (612) 626-2961 Fax: (612) 626-1434
E-Mail: baker084@umn.edu
- **Frank Ondrey, MD, PhD, FACS**, Otolaryngology
Telephone: (612) 624-5900
E-mail: ondre002@umn.edu
- **Rahel G. Ghebre, MD**, Gynecologic Oncology
Telephone: (612) 626-2613 Fax: (612) 626-0665
E-mail: 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
- **Jo-Anne H. Young, MD**, Infectious Disease
Telephone: (612) 624-9996 Fax: (612) 625-4410
E-mail: Vanbu004@umn.edu
- **Pat Fidler, RN**, Nurse Coordinator
Telephone: (612) 273-8480 Fax: (612) 273-2919
E-mail: pfidler1@fairview.org
- **Heather Zierhut, MS**, Genetic Counselor
Telephone: (612) 626-6743 Fax: (612) 273-2919
E-mail: hzierhu1@fairview.org

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University of Minnesota, Fanconi Anemia Comprehensive Care Program
University of Minnesota Medical Center, Amplatz Children's Hospital, Fairview,
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 patients 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 20-bed 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, 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

- **Zora R. Rogers, MD**, Associate Professor, Pediatric Hematology-Oncology
Telephone: (214) 456-2382 Fax: (214) 456-6133
E-mail: zora.rogers@utsouthwestern.edu

Clinical Practice Locations:

Center for Cancer and Blood Disorders

Children's Medical Center Dallas
1935 Medical District Drive
Dallas, TX 75235

Children's Medical Center Legacy

7601 Preston Road
Plano, Texas 75024

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*

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 RegistrySM

3001 Broadway Street NE, Suite 100

Minneapolis, MN 55413-1753

www.marrow.org

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

Email: *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.

Services Offered:

- ◆ We connect patients, doctors, donors and researchers to the resources they need to help more people live longer and healthier lives.
- ◆ Be The Match RegistrySM is the new name of the NMDP's registry
- ◆ 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 dial (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
- **Meilan Rutter, MD**, Associate Professor of Pediatrics, Division of Endocrinology
Telephone: (513) 636-4744
E-mail: meilan.rutter@cchmc.org

ENDOCRINOLOGY, cont'd

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

- **Anna Petryk, MD**, Pediatric Endocrinology
Telephone: (612) 624-5409 Fax: (612) 626-5262
E-mail: 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

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

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

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

(Continued on the next page)

GYNECOLOGY, cont'd

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*

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
Telephone: (612) 596-6100

Services Offered

- ◆ Hand and upper extremity surgery in the pediatric population

(Continued on the next page)

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

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

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

- **Brenda Diaz**, New Patient Coordinator
Telephone (781) 726-7337, ext. 101 Fax (781) 726-7310
E-mail: 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

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

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

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**, Associate Professor, Department of Otolaryngology (Ears, Nose, Throat), Head and Neck Surgery
Telephone: (301) 496-5369
E-mail: kimj@nidcd.nih.gov

Clinical Interests: Dizziness, Hereditary Hearing Loss, Balance Disorders, Acoustic Neuroma and skull base surgery, Otosclerosis, Cholesteatoma.

(Continued on the next page)

OTOLARYNGOLOGY, cont'd:

National Institutes of Health, cont'd

- **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*

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) 702-6149 Fax: (773) 702-3002
E-mail: *ecohen@medicine.bsd.uchicago.edu*

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

- **Everett Vokes, MD**, Interim Chief Executive Officer, University of Chicago Medical Center
Interim Dean, Division of the Biological Sciences and the Pritzker School of Medicine, Deputy
Director, Cancer Research Center
Telephone: (773) 702-9306 Fax: (773) 702-3002
E-mail: *evokes@medicine.bsd.uchicago.edu*

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

University of Minnesota, Fanconi Anemia Comprehensive Care Program

University of Minnesota Medical Center, Amplatz Children's Hospital, Fairview

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

OTOLARYNGOLOGY, cont'd:

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

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

- **Mark Hughes, MD, PhD**
Telephone: (313) 544-4006 Fax: (313) 544-4006
E-mail: pgd@genesisgenetics.org
- **Shannon Wiltse, MS, CGC**, Certified Genetic Counselor
Telephone: (313) 544-4006 Fax: (313) 544-4006
E-mail: counselor@genesisgenetics.org

Services Offered:

- ◆ Pre-pregnancy/pre-implantation diagnosis of FANCA, 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;

(Continued on the next page)

PRE-IMPLANTATION GENETIC DIAGNOSIS, cont'd:

The Genesis Genetics Institute, Genomic Technology Center, cont'd

- ◆ 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

E-mail: *rgiworld@gmail.com*

- Dana Pauling, MS, CGC
- Christina Lavin, MS, CGC
- Lama Eldahdah, MS, CGC

Services Offered:

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