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

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

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  E-mail: dawilliams@childrens.harvard.edu

• Colin Sieff, MB BCh
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  E-mail: 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

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

(Continued on the next page)
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 diepoxynbutane (DEB) test.


♦ Complementation analysis via retrovirus gene transfer.

♦ Fundamental research in DNA repair pathways, induced pluripotent stem cells and gene therapy.

♦ Referral for pre-implantation genetic diagnosis services at two sites in Boston if we find disease causing mutations.

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
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

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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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

• 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
• 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
• 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
• 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
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• 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
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• Susan R. Rose, MD, MEd, Professor of Pediatrics, Pediatric Endocrinology
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Cincinnati Children’s Hospital Medical Center, cont’d

- **Meilan Rutter, MD**, Associate Professor of Pediatrics, Division of Endocrinology  
  Telephone: 513-636-4744  
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- **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  
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- **Jill Huppert, MD, MPH**, Pediatric and Adolescent Gynecology  
  Telephone: 513-636-2911  
  Fax: 513-636-8844  
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- **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

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).
City Of Hope
1500 E. Duarte Rd.
Duarte, CA 91010
Telephone: 626-301-8442
E-mail: 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
- **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

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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
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  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
- **Nancy Barbach, CSW**
  E-mail: 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

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
www.fhcrc.org

Seattle Children’s Hospital
4800 Sand Point Way NE
Seattle, WA 98105
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

• 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

• 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

• 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

• 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.
  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.

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
  http://lab.rockefeller.edu/smogorzewska

• Arleen D. Auerbach, PhD
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  E-mail: auerbac@rockefeller.edu

• Erica Sanborn, MS, CGC
  Telephone: 212-327-8613   Fax: 212-327-8262
  E-mail: 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)
International Fanconi Anemia Registry (IFAR), cont’d

Co-Principal Investigators for the IFAR:

- **Farid Boulad, MD**  
  Memorial Sloan-Kettering Cancer Center, New York, NY  
  Telephone: 212-639-6684  
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  Head and Neck Surgeon  
  Weill Cornell Medical Center/New York Presbyterian Hospital, New York, NY  
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**Memorial Sloan-Kettering Cancer Center**

1275 York Ave.
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www.mskcc.org

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- **Mercedes Castiel, MD**, Gynecology  
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  E-mail: castielm@mskcc.org

- **Julia A. Kearney, MD**, Psychiatry and Pediatrics  
  Telephone: 646-888-0028  
  E-mail: Kearneyj@mskcc.org

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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
• 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.marrowfailure.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
• Blanche P. Alter, MD, MPH, FAAP
  Telephone: 301-402-9731   Fax: 301-212-5281
  E-mail: alterb@mail.nih.gov
• Neelam Giri, MD, FAAP
  Telephone: 301-594-7642   Fax: 301-212-5281
  E-mail: girin@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
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• Evan Shereck, MD, Assistant Professor of Pediatrics
  Telephone: 503-494-0829    Fax: 503-494-0714
  E-mail: 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    Pediatric Hematology/Oncology Academic Office
770 Welch Road, Suite 261   1000 Welch Road, Suite 300
Palo Alto, CA 94304    Palo Alto, CA  94304
www.lpch.org

Hematology/Oncology    Telephone: 650-723-5535
• Bertil Glader, MD, PhD, Professor, Pediatrics and Pathology
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• Kirsten Mouradian, RN, MSN, FNP, Hematology Nurse Practitioner
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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: kkrivovitch@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 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

• 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, Associate Professor, Department of Pediatrics, Division of Blood and Marrow Transplantation  
  Telephone: 612-626-2778     Fax: 612-626-2815  
  E-mail: macmi002@umn.edu
• Jakub Tolar, MD, PhD, Director, Stem Cell/Gene Therapies, Albert and Eva Corniea Chair, Associate Professor, Department of Pediatrics, Division of Blood and Marrow Transplantation  
  Telephone: 612-625-2912; Fax: 612-624-3913  
  Email: tolar003@umn.edu
• Anna Petryk, MD, Pediatric Endocrinology  
  Telephone: 612-624-5409     Fax: 612-626-5262  
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(Continued on the next page)
University of Minnesota, Fanconi Anemia Comprehensive Care Program, cont’d

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  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, CGC, Certified Genetic Counselor
  Telephone: 612-626-6743   Fax: 612-273-2919
  E-mail: 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), dietitian, 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);

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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

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; and
♦ Psychology, Social Work, Physical and Occupational Therapy services.
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.

**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
Telephone: 1-888-999-6743. Outside of the US: 612-632-3410
E-mail: 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 Registry®
Designated Treatment Program (DTP)
Cord Blood Registry
1200 Bayhill Drive, 3rd Floor
San Bruno, CA 94066
www.cordblood.com
Telephone: 1-888-932-6568

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

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
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

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 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
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

*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

- Heather Zierhut, MS, CGC, Certified Genetic Counselor
  Telephone: 612-626-6743   Fax: 612-273-2919
  E-mail: 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
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
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)
Shriners Hospital for Children, cont’d

- **Maureen Fulcher**, Nurse Assistant  
  Telephone: (215) 430-4204  
  E-mail: 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

- **Nancy Lemist**, New Patient Affairs Coordinator  
  Telephone: 781-726-7501  
  Fax: 781-726-7310  
  E-mail: 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.
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

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

**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

**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**, 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

**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

**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

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

- **Everett Vokes, MD**, John E. Ultmann 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

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
- **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

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.
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: 313-579-9650    Fax: 313-544-4006
  E-mail: pgd@genesisgenetics.org

- **Shannon DeWall, MS, CGC, Certified Genetic Counselor**
  Telephone: 313-579-9650    Fax: 313-544-4006
  E-mail: 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.

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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

- **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.