OUR MISSION

To find effective treatments and a cure for Fanconi anemia and to provide education and support services to affected families worldwide.

1801 Willamette Street, Suite 200
Eugene, OR 97401
1-541-687-4658
Toll Free: 1-888-FANCONI (inside the U.S. only)
Fax: 1-541-687-0548
www.fanconi.org
info@fanconi.org
www.facebook.com/fanconianemiaresearchfund
https://twitter.com/FAresearchfund

Staff

Laura Hays, PhD, Executive Director  laura@fanconi.org
Teresa Kennedy, MA, Director of Family Support Services  teresa@fanconi.org
Janae Peverill, Executive and Family Support Assistant  janae@fanconi.org
Cynthia Freeman, Special Projects Coordinator  cynthia@fanconi.org
Table of Contents

U.S. FA Treatment Resources
Bone Marrow Failure ........................................................................................................ 1
Bone Marrow Donor Registries ......................................................................................... 11
Cord Blood Registries ...................................................................................................... 11
Dermatology .................................................................................................................... 12
Endocrinology .................................................................................................................. 12
Gastroenterology ............................................................................................................. 13
Genetic Counseling ........................................................................................................ 13
Gynecology ..................................................................................................................... 14
Hand Surgeons ............................................................................................................... 14
Ophthalmology .............................................................................................................. 15
Otolaryngology (Ear, Nose, Throat) and Head & Neck Cancer .................................. 16
Pre-Implantation Genetic Diagnosis (PGD) ................................................................... 18
Radiation Oncology ........................................................................................................ 18

U.S. FA Testing Resources .............................................................................................. 19

International FA Treatment Resources
Australia ............................................................................................................................ 23
Austria .............................................................................................................................. 24
Brazil ............................................................................................................................... 24
Canada ............................................................................................................................ 25
China ............................................................................................................................... 25
Colombia ......................................................................................................................... 25
Czech Republic .............................................................................................................. 26
Denmark ........................................................................................................................ 26
France .............................................................................................................................. 26
Germany ........................................................................................................................ 27
India ............................................................................................................................... 28
Iran ................................................................................................................................. 28
Israel .............................................................................................................................. 28
Italy ................................................................................................................................. 29
Japan .............................................................................................................................. 30
Kenya ............................................................................................................................. 30
Lebanon .......................................................................................................................... 31
Mexico ............................................................................................................................. 31
Netherlands ..................................................................................................................... 32
New Zealand ................................................................................................................ 33
Republic of Korea .......................................................................................................... 33
Saudi Arabia ................................................................................................................ 33
Singapore ....................................................................................................................... 33
South Africa .................................................................................................................. 34
Spain ............................................................................................................................... 34
Turkey ............................................................................................................................ 36
United Kingdom ........................................................................................................... 36

International FA Testing Resources ............................................................................ 39

Index of Institutions and Clinicians ............................................................................... 43
U.S. Fanconi Anemia Treatment Resource Guide

 Editors’ note and disclaimer: The resource list provided in this guide is not comprehensive. Inclusion on the list does not imply endorsement by the Fanconi Anemia Research Fund, Inc. Families are encouraged to ask clinicians about their experience treating patients with Fanconi anemia.

**BONE MARROW FAILURE**

**Children’s Hospital Central California**

Department of Pediatric Hematology SC-62
9300 Valley Children’s Place
Madera, CA 93636 -8762
Telephone: 559-353-5460  Fax: 559-353-5095
Email: vbalasa@childrenscentralcal.org

- Laura Andrews, RN, Transplant Coordinator
- Vinod Balasa, MD. Director of Hematology/Oncology
- Kelly Folmer, RN, CPNP
- Terea Giannetta, DNP, CPNP, Nurse Practitioner
- Catherine Hanson, LCSW
- Nancy G. Hatcher, MSW, Clinical Social Worker
- Mary Beth Jones, Child Life Coordinator
- William Koole, Pharm.D
- Shari Langer, PhD, Clinical Psychologist
- J. Daniel Ozeran, MD, PhD
- Latha Rao, MD
- Faisal Razzaqi, MD
- Ruth Rolen-Martinez, RN, BSN, Clinical Coordinator
- Wendy Tcheng, MD
- Ruetima Titaphiwatanakun, MD
- Pamela Young, RD

Services Offered:

Children’s Hospital Central California provides diagnostic, treatment and referral services to children ages birth to 21 years in California’s Central Valley, at the only pediatric hospital between Los Angeles and San Francisco and the largest children’s hospital between San Diego and San Francisco. Patients are seen and treated from initial diagnosis to and beyond bone marrow transplant for which patients are referred to nationally recognized transplant centers. Patients receive specialty care within the Fanconi anemia treatment program as well as from Genetics, Orthopaedics, Cardiology, Behavioral Health Sciences and other specialty services. Patients with Fanconi anemia are provided supportive, educational, and consultative services to further enhance care.

**Children’s Hospital Los Angeles, Keck School of Medicine, University of Southern California**

4650 Sunset Boulevard, MS #62
Los Angeles, CA 90027

- Neena Kapoor, MD. Division of Research Immunology & Bone Marrow Transplant
  Telephone: 323-361-2546  Fax: 323-361-8068
  Email: nkapoor@chla.usc.edu

**Children’s Hospital of Wisconsin**

MACC Fund Research Center, Suite 3018
8701 Watertown Plank Road
Milwaukee, WI 53226

Monica Thakar, MD
Telephone: 414-955-4170  Fax: 414-955-6543
Email: mthakar@mcw.edu

Services Offered:

- Evaluation of new and previously diagnosed patients;
- Personalized treatment regimens and coordination of care by specialists in hematology, bone marrow transplantation, cardiology, endocrinology, genetics, gastroenterology, nephrology, urology, orthopedics, social work;
- Stem cell collection, storage, and infusion;
- Expertise in matched sibling donor, unrelated donor, and haploidentical (alternative donor) transplantation for Fanconi anemia;
- Collaborations with Fred Hutchinson Cancer Research Center and Memorial Sloan-Kettering Cancer Center in alternative donor clinical trials.

**Note:** FANCD2 immunoblot=FANCD2 western=FANCD2 ubiquitination.
BONE MARROW FAILURE

Cincinnati Children’s Hospital Medical Center
Fanconi Anemia Comprehensive Care Center
MLC 11013
3333 Burnet Avenue
Cincinnati, OH 45229
www.cincinnatichildrens.org

• Erica L. Goodridge, RN, BSN, CPN, Care Manager,
  Fanconi Anemia Comprehensive Care Center
  Telephone: 513-636-3218  Fax: 513-636-7951
  Email: erica.goodridge@cchmc.org

• Stella Davies, MBBS, PhD, MRCP, Director,
  Bone Marrow Transplantation and Immune Deficiency
  Jacob G. Schmidlapp Endowed Chair
  Professor, UC Department of Pediatrics
  Telephone: 513-636-2469  Fax: 513-636-3549
  Email: stella.davies@cchmc.org

• Richard Harris, MD, Professor of Clinical Pediatrics
  University of Cincinnati College of Medicine
  Division of Blood and Marrow Transplantation and
  Immune Deficiency
  Cancer and Blood Diseases Institute
  Telephone: 513-803-9063  Fax: 513-636-7951
  Email: richard.harris@cchmc.org

• Lesley Breech, MD, Division Director, Pediatric and
  Adolescent Gynecology
  Associate Professor, UC Department of Surgery
  University of Cincinnati Department of Obstetrics and
  Gynecology
  Telephone: 513-636-2960  Fax: 513-636-8844
  Email: lesley.breech@cchmc.org

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

• Jens Goebel, MD, Professor, Nephrology
  Telephone: 513-636-0993
  Email: jens.goebel@cchmc.org

• Sara C. Knapke, MD, Clinical Manager and Certified
  Genetic Counselor
  Telephone: 513-803-0211
  Email: sara.knapke@cchmc.org

• Samuel Kocoshis, MD, Professor
  Telephone: 513-636-4415
  Email: samuel.kocoshis@cchmc.org

• Sarah Lawson, MD, Assistant Professor, Endocrine
  Telephone: 513-736-4465
  Email: sarah.lawson@cchmc.org

• Nancy Doan Leslie, MD, Director, Biochemical Genetics
  Laboratory
  Director, ABMG-Accredited Clinical Training Program
  Professor, UC Department of Pediatrics
  Telephone: 513-803-2438  Fax: 513-636-7297
  Email: nancy.leslie@cchmc.org

• Charles T. Mehlman, MD, Director, Musculoskeletal
  Outcomes Research
  Co-Director, Brachial Plexus Center
  Professor, Division of Pediatric Surgery
  Telephone: 513-636-4785  Fax: 513-803-3928
  Email: charles.mehlman@cchmc.org

• Parinda Mehta, MD, Associate Professor,
  UC Department of Pediatrics
  Telephone: 513-636-4913  Fax: 513-803-1969
  Email: parinda.mehta@cchmc.org

• Eugene Minevich, MD, FACS, FAAP, Director,
  Stone Program
  Professor, UC Department of Pediatrics
  Telephone: 513-636-4975
  Email: kasiani.myers@cchmc.org

• Kasiarni Myers, MD, Assistant Professor,
  U.S. Department of Pediatrics
  Telephone: 513-636-7287
  Email: kasiarni.myers@cchmc.org

• Susan R. Rose, MD, MEd, Professor,
  UC Department of Pediatrics, Endocrine
  Telephone: 513-636-4744
  Email: susan.rose@cchmc.org

• Michael Rutter, MD, Pediatric Otolaryngologist and
  Director of Clinical Research
  Professor, UC Department of Pediatrics
  Otolaryngology - Head and Neck Surgery
  Telephone: 513-636-4881  Fax: 513-636-8133
  Email: mike.rutter@cchmc.org

• Thomas Ryan, MD, Assistant Professor, Cardiology
  Telephone: 513-636-9282
  Email: thomas.ryan@cchmc.org

• Mary Sutton, MD, Assistant Professor,
  UC Department of Pediatrics
  Telephone: 513-636-4222
BONE MARROW FAILURE

- Robert E. Wood, MD, PhD, Director, Pulmonary Bronchoscopy Department
  Professor, UC Department of Pediatrics
  Telephone: 513-636-2776 Fax: 513-636-3845
  Email: rewood@chmc.org

Services Offered:
- Evaluation of new and previously diagnosed patients;
- Personalized treatment regimens by specialists in bone marrow transplantation, cardiology, endocrinology, genetics, hematology, nephrology, urology, orthopedics, hand surgery, social work, and family support network;
- Pharmacological and other clinical trials (e.g., cytokines and flavonoids);
- Fanconi anemia repository for samples and data;
- Expertise in matched sibling donor and unrelated donor transplantation for Fanconi anemia;
- Fanconi anemia complementation and mutation analysis;
- Stem cell collection, storage, and reinfusion;
- Collaboration with, International Fanconi Anemia Registry (Arleen Auerbach, PhD).

City Of Hope
1500 E. Duarte Road
Duarte, CA 91010
Telephone: 626-301-8442

- Joseph Rosenthal, MD, Chair, Department of Pediatrics, Pediatric Hematology/Hematopoietic Cell Transplantation
  Email: jrosenthal@coh.org

- Anna Pawlowska, MD, Director, Pediatric Hematology/Hematopoietic Cell Transplantation
  Email: apawlowska@coh.org

- Nicole Karras, MD, Staff Physician, Pediatric Hematology/Hematopoietic Cell Transplantation
  Email: nkarras@coh.org

- Saro Armenian, MD, MPH, Associate Professor, Pediatric Hematology/Oncology and Population Sciences, Division of Outcomes Research
  Email: sarmenian@coh.org

- Julie Wolfson, MD, Staff Physician, Pediatrics; Assistant Professor, Population Sciences & Pediatrics
  Email: jwolfson@coh.org

- Debbie Hitt, RN, BSN, CPN, Nurse-Coordinator, Pediatric Hematology/Hematopoietic Cell Transplantation
  Email: jwolfson@coh.org

- Lisa Gutierrez, RN, MSN, CPNP, CPHON, Nurse Practitioner, Pediatrics
  Email: lisagutierrez@coh.org

- Nadia Ewing, MD, Director, Pediatric Hematology
  Email: newing@coh.org

- Lisa Pullens, RN, BSN, Nurse Coordinator, Pediatric Hematology
  Email: lpullens@coh.org

- Joyce Collins, PhD, Director, Cytogenetics
  Email: jcollins@coh.org

- Christina Cabanillas, LCSW, Social Worker, Pediatric Hematology/Hematopoietic Cell Transplantation
  Email: ccabanillas@coh.org

- Renee Ortiz, LCSW, Social Worker, Pediatric Hematology/Hematopoietic Cell Transplantation
  Email: reortiz@coh.org

- April Sorrell, MD, Pediatric Hematology/Hematopoietic Cell Transplantation and Pediatric Clinical Cancer Genetics

- Smita Bhatia, MD, Pediatrics, Hematology/Hematopoietic Cell Transplantation and Director, Population Sciences

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

Cohen Children’s Medical Center of New York, Bone Marrow Failure Program
Division of Hematology/Oncology and Stem Cell Transplantation
269-01 76th Avenue, Rm. 255
New Hyde Park, NY 11040

- Adrianna Vlachos, MD, Assistant Professor of Pediatrics
  Head, Bone Marrow Failure Program and Associate Head, Stem Cell Transplant Program
  Telephone: 718-470-3611 Fax: 718-343-2961
  Email: avlachos@lij.edu
BONE MARROW FAILURE

- Johnson M. Liu, MD. Les Nelkin Professor of Pediatrics
  Head, Section of Experimental Hematology and Les
  Nelkin Memorial Pediatric Oncology Research
  Laboratory
  Telephone: 718-470-7174
  Email: jliu3@nshs.edu

- Jeffrey M. Lipton, MD. PhD. Professor of Pediatrics
  Chief, Division of Hematology/Oncology and Stem Cell
  Transplantation
  Telephone: 718-470-3460
  Email: jlipton@lij.edu

- Nancy Barbach, LCSW. Social Worker, Hematology
  Oncology and Stem Cell Transplantation
  Telephone: 718-470-3286
  Email: nbarbach@nshs.edu

Services Offered:
- Bone Marrow Failure Clinic offering comprehensive
  evaluation of adult and pediatric FA patients by an
  experienced team of multi-disciplinary specialists directed
  by medical and pediatric hematologists;
- Hematopoietic Stem Cell Transplant Program offering
  expertise in transplantation in bone marrow failure
  syndromes;
- Experimental Hematology Program studying molecular
  mechanisms of hematopoietic failure and oncogenesis in
  FA and other bone marrow failure syndromes.

Fanconi Anemia and Bone Marrow Failure
Multi-disciplinary Clinic at the Dana-
Farber/Boston Children’s Cancer and Blood
Disorders Center
Dana-Farber Cancer Institute
450 Brookline Avenue
Boston, MA 02215

- Eva C. Guinan, MD. Associate Professor of Radiation
  Oncology
  Director, Translational Research BWH/DFCI Department
  of Radiation Oncology
  Telephone: 617-632-4932 Fax: 617-632-3770
  Email: Eva_Guinan@dfci.harvard.edu

- Lisa L. Brennan, BSN, RN. Research Nurse
  Email: Lisa_brennan@dfci.harvard.edu

Services Offered:
- Comprehensive evaluation;
- Second opinions;
- Pre- and post-transplantation evaluation;
- Follow-up care and planning.

Boston Children’s Hospital
300 Longwood Avenue
Boston, MA 02115
http://www.childrenshospital.org/fa-bmf

- David A. Williams, MD
  Telephone: 617-919-2697
  Email: dawilliams@childrens.harvard.edu

- Colin Sieff, MB BCh
  Telephone: 617-355-2367
  Email: colin.sieff@childrens.harvard.edu

- Mary Cogan, CPNP, RN, CPHON
  Telephone: 617-355-8246 Fax: 617-730-0641
  Email: mary.cogan@childrens.harvard.edu

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

- Alan D’Andrea, MD
  Telephone: 617-632-2080
  Email: alan_dandrea@dfci.harvard.edu

- Lisa A. Moreau, MS, CLSpCG
  Telephone: 617-632-6302
  Email: lisa_moreau@dfci.harvard.edu

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

Services Offered:
- Our Nurse Practitioner arranges a comprehensive
evaluation for each new patient, including confirmation of
diagnosis, genetic typing, HLA typing, and a multi-system
evaluation. The team carefully examines previous
diagnostic test results and past medical history to guide the
initial evaluation in the multi-disciplinary clinic. This
results in a written summary and recommendations for the
referring physician and the patient’s family. Ongoing care
may continue at Children’s or in partnership with the
referring physician. Psychosocial support is available and
an important part of our long-term care of families of
patients with serious diseases.

- A variety of innovative clinical trials are available for
  enrollment. Two current studies for patients with Fanconi
  anemia are: 1) the use of danazol, an androgen and 2) a
  hematopoietic stem cell transplantation trial for those
  lacking a genotypically identical donor.
- Diagnosis of new FA patients through Clinical Laboratory
  Improvement Act (CLIA)-certified diepoxybutane (DEB)
  test.
- Facilitation of DNA mutation identification via
  CAP/CLIA-certified DNA sequencing in the Laboratory
  Medicine Department at Boston Children’s Hospital
  coordinated with Dr. Bai-Lin Wu and Ann Reinhard.
  Current available testing for FANCA, FANCC, and
  FANCG are listed at www.genetests.org. Genetic
  Counselor: Ann E. Reinhard, MS, CGC, phone:
  617-355-4907, ann.reinhard@childrens.harvard.edu.
- Complementation analysis via retrovirus gene transfer.
- Fundamental research in DNA repair pathways, induced
  pluripotent stem cells and gene therapy.
- Referral for pre-implantation genetic diagnosis services at
  two sites in Boston if we find disease-causing mutations.

Fred Hutchinson Cancer Research Center
1100 Fairview Ave N
Seattle, WA 98101
Telephone: 206-667-5000
www.fhcrc.org

Seattle Children’s Hospital
4800 Sand Point Way NE
Seattle, WA 98105
www.seattlechildrens.org

- Akiko Shimamura, MD, PhD, Director, Compregensive
  Marrow Failure/MDS Program, Pediatric Hematology-
  Oncology, Seattle Children’s Hospital
  Member, Fred Hutchinson Cancer Research Center
  Professor of Pediatrics, University of Washington School
  of Medicine
  Telephone: 206-987-2106 Fax: 206-987-3946
  Email: ashimamu@fredhutch.org

- Hans-Peter Kiem, MD, Member, Fred Hutchinson
  Cancer Research Center
  Investigator, Markey Molecular Medicine Center
  Adjunct Associate Professor of Pathology
  Associate Professor of Medicine, University of
  Washington School of Medicine
  Telephone: 206-667-4425 Fax: 206-667-6124
  Email: hkiem@fredhutch.org

- K. Scott Baker, MD, MS, Member and Director,
  Pediatric Blood and Marrow Transplantation and
  Survivorship Programs, Fred Hutchinson Cancer
  Research Center and Seattle Children’s Hospital
  Professor of Pediatrics, University of Washington School
  of Medicine
  Telephone: 206-987-2106 Fax: 206-667-5899
  Email: ksbbaker@fredhutch.org

- Ann Woolfrey, MD, Director, Unrelated Donor Program
  Member, Fred Hutchinson Cancer Research Center,
  Pediatric Blood and Marrow Transplant Program
  Professor of Pediatrics, University of Washington School
  of Medicine
  Telephone: 206-667-4453 Fax: 206-667-4310
  Email: awoolfre@fredhutch.org

- Jennifer Adair, PhD, Clinical Research Associate
  Fred Hutchinson Cancer Research Center
  Telephone: 206-667-7110 Fax: 206-667-6124
  Email: jadair@fredhutch.org

- Pam Becker, MD, PhD, Associate Professor of
  Medicine, University of Washington School of Medicine,
  Department of Hematology
  Telephone: 206-288-2294 Fax: 206-543-3560

Services Offered:
- Comprehensive Fanconi Anemia Program including
  evaluation and management of new and previously
  diagnosed pediatric and adult patients with FA;
- Personalized treatment regimens by specialists in
  hematology, bone marrow transplantation, cardiology,
  endocrinology, genetics, gastroenterology, nephrology,
  urology, orthopedics, and social work;
- Gene therapy trial; Fanconi anemia repository for samples
  and data;
- Stem cell collection, storage, and reinfusion;
- Expertise in matched sibling donor, unrelated donor, and
  haploidentical (alternative donor) transplantation for
  Fanconi anemia;
- Collaboration with Hospital de Clinicas, University of
  Parana, Brazil (Carmem Bonfim, MD and Ricardo
  Pasquini, MD, PhD).
BONE MARROW FAILURE

Hackensack University Medical Center
Tomorrow’s Children Institute
30 Prospect Avenue
Hackensack, NJ 07601
www.HackensackUMC.org

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

- Barbara Adler-Brecher, MS
  Email: badler-brecher@hackensackumc.org

Services Offered:
- Diagnosis and genetic counseling;
- Comprehensive medical treatment including gynecology and ENT specialists;
- Matched sibling and unrelated donor transplants.

International Fanconi Anemia Registry (IFAR)
The Rockefeller University
Part of New York Consortium for Inborn Errors of Hematopoiesis and Immunity (see also, Memorial Sloan Kettering Cancer Center, New York Presbyterian Hospital, and Hospital for Special Surgery)
Laboratory of Genome Maintenance
1230 York Avenue, Box 182
New York, NY 10065
http://lab.rockefeller.edu/smogorzewska/ifar/
Facebook: Fanconi Anemia Registry or Agata Smogorzewska

- Agata Smogorzewska, MD, PhD, Principal Investigator
  Telephone: 212-327-7850, or 8862 Fax: 212-327-8262
  Email: asmogorzewska@rockefeller.edu
  http://lab.rockefeller.edu/smogorzewska

- Arleen D. Auerbach, PhD, Co-Investigator
  Telephone: 212-327-7533, or 8862 Fax: 212-327-8262
  Email: auerbac@rockefeller.edu

- Jennifer Kennedy, MS, CGC, Genetic Counselor/Study Coordinator
  Telephone: 212-327-8612, or 8862 Fax: 212-327-8262
  Email: jkennedy@rockefeller.edu

Genetic Services on Research Protocol:
- International Fanconi Anemia Registry (IFAR);
- Mutation screening of probands (gene specific sequencing, next generation sequencing, whole exome sequencing, SNP analysis, and/or CHG) for genes under investigation by the laboratory;
- Genomic analysis of tumor tissue from enrolled participants: surgical samples needed;
- Derivation of lymphoblastoid cell line for complementation testing; maintenance of Fanconi anemia cell and DNA repositories;
- Genetic counseling for individuals involved in the IFAR, and their family members.

Testing Services on Research Protocol:
- Mutation analysis (research)
- FANCD2 western blot (research)

Co-Principal Investigators for the IFAR:
- Farid Boulad, MD, Memorial Sloan-Kettering Cancer Center, New York, NY
  Telephone: 212-639-6684 Fax: 212-717-3555
  Email: bouladf@mskcc.org

- Stella Davies, MBBS, PhD, MRCP, Cincinnati Children’s Hospital Medical Center
  Cincinnati, OH
  Telephone: 513-636-1371 Fax: 513-636-3459
  Email: stella.davies@cchmc.org

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

- David I. Kutler, MD, Head and Neck Surgeon, Weill Cornell Medical Center/New York Presbyterian Hospital, New York, NY
  Telephone: 646-962-4323, 646-962-0100
  Email: dik2002@med.cornell.edu

Memorial Sloan-Kettering Cancer Center
Part of New York Consortium for Inborn Errors of Hematopoiesis and Immunity (see also, Rockefeller University, New York Presbyterian Hospital, and Hospital for Special Surgery)
1275 York Avenue
New York, NY 10065
Email: www.mskcc.org

- Farid Boulad, MD, Medical Director, Pediatric Day Hospital
  Attending Physician
  Bone Marrow Transplant Service
  Department of Pediatrics
Mount Sinai School of Medicine
Novel Therapeutics and Stem Cell Transplantation Program
Division of Hematology-Oncology
Annenberg 24-42, Box 1079
One Gustave L. Levy Place
New York, NY 10029

Christopher Walsh, MD, Associate Professor of Medicine
Telephone: 212-241-3443
Email: christopher-e.walsh@msnyuhealth.org
Gynecology Consultation Service at the NIH Clinical Center; Eunice Kennedy Shriver National Institute of Child Health and Human Development
10 Center Dr. Suite 1-3140
Bethesda, MD 20892

- Pamela Stratton, MD, Chief, Gynecology Consult Service
  Telephone: 301-496-9079  Fax: 301-480-6703
  Email: strattop@mail.nih.gov

Services Offered:
- Gynecology consulting service is only available to FA patients/family members enrolled in Blanche Alter’s protocol.

Head and Neck Surgery Branch at the NIH
Building 10, Room 4-2732
10 Center Drive
Bethesda, MD 20892

- Carter Van Waes, MD, PhD, Chief Head and Neck Surgery Branch
  Clinical Director, National Institute on Deafness and other Communication Disorders
  Telephone: 301-402-4216  Fax: 301-402-1140
  Email: vanwaesc@nidcd.nih.gov

Dermatology Consultation Service at the NIH Clinical Center; Center for Cancer Research
Building 10, Room 12N238
Bethesda, MD 30892-1908

- Edward Cowen, MD, Head, Dermatology Consultation Service
  Telephone: 301-496-4299  Fax: 301-402-2943
  Email: cowene@mail.nih.gov

Services Offered:
- Dermatology consulting service is only available to FA patients/family members enrolled in Blanche Alter’s protocol.

Oregon Health & Science University
Doernbecher Children’s Hospital
3181 S.W. Sam Jackson Park Road
Portland, OR 97239

- Peter Kurre, MD, Professor of Pediatrics
  Telephone: 503-494-1543 Fax: 503-494-0714
  Email: kurrepe@ohsu.edu

- Evan Shereck, MD, Associate Professor of Pediatrics
  Telephone: 503-494-0829 Fax: 503-494-0714
  Email: shereck@ohsu.edu

Services Offered:
- Diagnostic evaluation and genetic counseling for FA;
- Comprehensive medical treatment;
- Stem cell transplantation;
- Research studies investigating molecular diagnostics, cytogenetics, complementation group subtyping, leukemogenesis, and genetics of Fanconi anemia.

Stanford School of Medicine
The Bass Center for Childhood Cancer and Blood Diseases
725 Welch Road
Palo Alto, CA 94304
www.stanfordchildrens.org

Pediatric Hematology/Oncology Academic Office
1000 Welch Road, Suite 300
Palo Alto, CA 94304

Hematology/Oncology
Telephone: 650-723-5535

- Bertil Glader, MD, PhD, Professor, Pediatrics and Pathology
  Email: bglader@stanford.edu

- Michael Jeng, MD, Associate Professor, Pediatrics
  Email: mjeng@stanford.edu

- Anu Narla, MD, Assistant Professor, Pediatrics
  Email: anunarla@stanford.edu

- Judith Lea, RN, MSN, PNP, Hematology Nurse Practitioner
  Email: jlea@stanfordchildrens.org

- Kirsten Mouradian, RN, MSN, FNP, Hematology Nurse Practitioner
  Email: kmouradian@stanfordchildrens.org

Stem Cell Transplant
Telephone: 650-725-9250

- Kenneth Weinberg, MD, Professor, Pediatrics
  Email: kw1@stanford.edu

- Rajni Agarwal, MD, Assistant Professor, Pediatrics
  Email: rajnia@stanford.edu
BONE MARROW FAILURE

- Sandhya Kharbanda, MD. Assistant Professor, Pediatrics
  Email: ksandhya@stanford.edu

- Karen Kristovich, RN, MSN, PNP, Stem Cell Transplant Nurse Practitioner
  Email: kkristovich@stanfordchildrens.org

- Elizabeth Schnorr, RN, PNP, Stem Cell Transplant Coordinator
  Email: eschnorr@stanfordchildrens.org

- Donna Reimer, RN, Stem Cell Transplant Coordinator
  Email: dreimer@stanfordchildrens.org

- Gayle Humphrey, RN, Stem Cell Transplant Coordinator
  Email: ghumphrey@stanfordchildrens.org

Services Offered:
- Diagnostic evaluation for Fanconi anemia and other bone marrow failure syndromes;
- Comprehensive care and long-term follow-up of new and previously diagnosed patients;
- Stem cell transplantation with matched related donor, matched unrelated donor, umbilical cord blood, and peripheral blood stem cells.

Texas Children’s Hospital
1102 Bates, FC1200
Houston, TX 77030

- Alison Bertuch, MD, PhD
  Telephone: 832-824-4579
  Email: abertuch@txch.org

University of Minnesota
Fanconi Anemia Comprehensive Care Program
University of Minnesota Medical Center and Masonic Children's Hospital
MMC 366
420 Delaware Street, S.E.
Minneapolis, MN 55455
Telephone: 612-273-2800
http://bmt.umn.edu/fanconi-anemia

- John E. Wagner, MD. Fanconi Anemia Comprehensive Care Program Leader, Director, Division of Hematology/Oncology and Blood and Marrow Transplantation
  CCRF/Hageboeck Family Chair in Pediatric Oncology & Clinical Director, Stem Cell Institute
  Telephone: 612-626-2961 Fax: 612-626-4074
  Email: wagne002@umn.edu

- Margaret L. MacMillan, MD. Fanconi Anemia Comprehensive Care Program Leader
  Associate Professor, Department of Pediatrics, Division of Blood and Marrow Transplantation
  Telephone: 612-626-2778 Fax: 612-626-2815
  Email: macmi002@umn.edu

- Jakub Tolar, MD, PhD. Director, Stem Cell/Gene Therapies
  Albert and Eva Corniea Chair
  Associate Professor, Department of Pediatrics, Division of Blood and Marrow Transplantation
  Telephone: 612-625-2912 Fax: 612-624-3913
  Email: tolar003@umn.edu

- Anna Petryk, MD, Pediatric Endocrinology
  Telephone: 612-624-5409 Fax: 612-626-5262
  Email: petry005@umn.edu

- Sarah Jane Schwarzenberg, MD, Pediatric Gastroenterology
  Telephone: 612-624-1133 Fax: 612-626-0639
  Email: schwa005@umn.edu

- Frank Ondrey, MD, PhD, FACS, Otolaryngology
  Telephone: 612-624-5900
  Email: ondre002@umn.edu

- Rahel G. Ghebre, MD, Gynecologic Oncology
  Telephone: 612-626-2613 Fax: 612-626-0665
  Email: ghebr004@umn.edu

- Ann E. Van Heest, MD, Dept. of Orthopaedic Surgery
  Telephone: 612-273-8086 Fax: 612-273-7959
  Email: Vanhe003@umn.edu

- Jo-Anne H. Young, MD, Infectious Disease
  Telephone: 612-624-9996 Fax: 612-625-4410
  Email: Vanbu004@umn.edu

- Pat Fidler, RN, Nurse Coordinator
  Telephone: 612-273-8480 Fax: 612-273-2919
  Email: pfidler1@fairview.org

- Rebecca Tryon, MS, CGC, Genetic Counseling
  Telephone: 612-624-1510 Fax: 612-624-6645
  Email: rtryon1@fairview.org

Journey Clinic
Center for Pediatric Blood and Marrow Transplantation
East Building, Ninth Floor
2450 Riverside Avenue
Minneapolis, MN 55454
http://bmt.umn.edu/
Telephone: 612-273-2800 Fax: 612-273-2919
BONE MARROW FAILURE

Services Offered:
- The University of Minnesota Fanconi Anemia Comprehensive Care Program (FACCP) utilizes a 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 in the new Children’s Hospital and a 30-bed adult inpatient unit and state of the art outpatient bone marrow transplantation clinic;
- Genetic counseling and coordination of complementation group analysis, mutation screening, somatic mosaicism studies, and other genetic testing options including prenatal genetic testing and pre-implantation genetic diagnosis (PGD);
- Family support services including nurse coordination, social work, genetic counseling, care-partners, and child and family life specialists to assist families throughout the diagnostic, transplantation, and post-transplantation processes;
- Family umbilical cord blood banking;
- Ongoing research in stem cell biology, mosaicism, genetic correction of stem cells, mechanisms of bone marrow failure, and novel treatments with collaborators around the country.

University of Texas Southwestern Medical Center
Pediatric Bone Marrow Failure Program
Children’s Health Dallas
Margaret Allen Gill Center for Cancer and Blood Disorders
1935 Medical District Drive
Dallas, TX 75235
Telephone: 214-456-2382 or 214-456-6102
Email: BoneMarrowFailure@UTSouthwestern.edu

- Zora R. Rogers, MD, Professor of Pediatrics, Hematology-Oncology, Clinical Director, Hematology and Bone Marrow Failure Program
  Email: zora.rogers@utsouthwestern.edu

- Tiffany Simms-Waldrip, MD, Assistant Professor of Pediatrics, Hematology-Oncology
  Head, Bone Marrow Failure Stem Cell Transplant Program
  Email: tiffany.simms-waldrip@utsouthwestern.edu

Services Offered:
- Consultation and education for new and previously diagnosed patients and their families;
- Comprehensive clinical management of pediatric Fanconi anemia patients;
- Stem cell transplantation for Fanconi anemia; stem cell collection and reinfusion;
- Disease based follow-up post transplantation for Fanconi anemia;
- Coordinated referral to institutional subspecialists in cardiology, endocrinology, gastroenterology, dental/oral-maxillo-facial surgery, nephrology, hand and orthopedic surgery interested in the unique needs of persons with Fanconi anemia;
- Psychology, social work, physical and occupational therapy services.
Delete Blood Cancer DKMS

100 Broadway, 6th Floor
New York, NY 10005
www.dkmsamericas.org
Telephone: 1-866-340- 3567
Email: info@dkmsamericas.org

Delete Blood Cancer DKMS is committed to the fight against blood diseases like leukemia and Fanconi anemia, and strives to give every blood cancer patient a second chance at life by recruiting bone marrow donors from every race and ethnicity. We inspire hope by matching our donors with patients from around the world who are in need of a bone marrow transplant.

Delete Blood Cancer DKMS:
• is the world’s largest bone marrow donor center, with more than 3 million registered donors;
• can register new bone marrow donors anywhere in the U.S;
• performs HLA- A*, B*, C*, DR* high-resolution typing on every registered donor, minimizing the search time for finding the best possible donor match for a patient;
• offers doctors immediate search of our database;
• does not require new donors to pay the $65 registration fee.

National Marrow Donor Program®/Be The Match®

3001 Broadway Street NE
Minneapolis, MN 55413-1753
www.bethematch.org
Telephone: 1-888-999-6743
Outside of the U.S: 612-632-3410
Email: patientinfo@nmdp.org

Be The Match helps patients with leukemia, lymphoma and other diseases who need a marrow or umbilical cord blood transplant. People can join the Be The Match Registry® - the world’s largest listing of potential marrow donors and donated cord blood units - contribute financially, and volunteer. Patients and their families can also turn to Be The Match for support and resources before, during, and after transplant. Be The Match is operated by the National Marrow Donor Program® (NMDP), a nonprofit organization that matches patients with donors, educates health care professionals, and conducts research so more lives can be saved. Learn more at BeTheMatch.org/patient.

Services Offered:
Be The Match has a team dedicated to supporting patients, caregivers and families before, during, and after transplant. We offer confidential one-on-one support, financial guidance, and free educational resources. Our goal is to get you what you need, when you need it. We offer support in more than 100 languages, including Spanish bilingual staff and translated materials.

CORD BLOOD REGISTRIES

Cord Blood Registry®

Designated Treatment Program (DTP)
Cord Blood Registry
1200 Bayhill Drive, 3rd Floor
San Bruno, CA 94066
www.cordblood.com
Telephone: 1-888-932-6568

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

Families wishing to store their newborn’s umbilical cord blood stem cells for a family member diagnosed with a life-threatening disease treatable by donor stem cells (including Fanconi anemia) are encouraged to apply for CBR’s Designated Treatment Program. If eligible, CBR will provide the collection kit and process and store the newborn’s cord blood and cord tissue sample for five years without any cost to the family. The family member must be a first-degree blood relative (full-sibling or parent) to the newborn and have an oncologist/hematologist or other treating physician agree that the stem cells can be used for treatment.
Services Offered:
- Dermatology consulting service is only available to FA patients/family members enrolled in Blanche Alter's protocol.

**Brigham and Women’s Hospital**

Brigham Dermatology Associates
221 Longwood Avenue
Boston, MA 02115

- Jennifer Lin, MD,
  Telephone: 617-732-4918  Fax: 617-582-6060
  Email: jylin@partners.org

---

**Cincinnati Children’s Hospital Medical Center**

**Fanconi Anemia Comprehensive Care Center**

3333 Burnet Avenue
Cincinnati, OH 45229

- Susan R. Rose, MD, MEd, Professor of Pediatrics, Pediatric Endocrinology
  Telephone: 513-636-4744
  Email: susan.rose@cchmc.org

**University of Minnesota**

**Fanconi Anemia Comprehensive Care Program**

**University of Minnesota Medical Center and Masonic Children's Hospital**

East Bldg Rm MB671
2450 Riverside Avenue
Minneapolis, MN 55454

- Anna Petryk, MD, Pediatric Endocrinology
  Telephone: 612-624-5409 Fax: 612-626-5262
  Email: petry005@umn.edu
Cincinnati Children’s Hospital Medical Center
Fanconi Anemia Comprehensive Care Center
3333 Burnet Avenue
Cincinnati, OH 45229

- Samuel Kocoshis, MD, Professor
  Telephone: 513-636-4415
  Email: samuel.kocoshis@cchmc.org

University of Minnesota
Fanconi Anemia Comprehensive Care Program
University of Minnesota Medical Center and
Masonic Children's Hospital
East Building, 6th Floor
2450 Riverside Avenue
Minneapolis, MN 55454

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

The Rockefeller University
Part of New York Consortium for Inborn Errors of Hematopoiesis and Immunity (see also, Memorial Sloan Kettering Cancer Center, New York Presbyterian Hospital, and Hospital for Special Surgery)
1230 York Avenue Box 182
New York, NY 10065
Fax: 212-327-8262
Facebook: Fanconi Anemia Registry or Agata Smogorzewska (PI of IFAR)

- Jennifer Kennedy, MS, CGC, Certified Genetic Counselor*
  Telephone: 212-327-8612
  Email: jkennedy@rockefeller.edu

*Genetic counseling provided for IFAR participants and their family members. Please see page 6 for more information about IFAR.

Journey Clinic
Center for Pediatric Blood and Marrow Transplantation
East Building, Ninth Floor
2450 Riverside Avenue
Minneapolis, MN 55454
Website: http://bmt.umn.edu/world-class-bmt-program/fanconi-anemia.php
Telephone: 612-273-2800  Fax: 612-273-2919

- Rebecca Tryon, MS, CGC
  Telephone: 612-624-1510  Fax: 612-624-6645
  Email: rtryon1@fairview.org
Eunice Kennedy Shriver National Institute of Child Health and Human Development

Bldg 10, CRC, Room 1-3140
10 Center Dr. MSC 1109
Bethesda, MD 20892-1109

- Pamela Stratton, MD, Chief, Gynecology Consult Service, Program in Reproductive and Adult Endocrinology
  Telephone: 301-496-9079 Fax: 301-480-6703
  Email: strattop@mail.nih.gov

University of Minnesota

Fanconi Anemia Comprehensive Care Program

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

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

- Rahel G. Ghebre, MD, Gynecologic Oncology
  Telephone: 612-626-2613 Fax: 612-626-0665
  Email: ghebr004@umn.edu

The New York Presbyterian Hospital

Weill Cornell Medical Associates

Part of New York Consortium for Inborn Errors of Hematopoiesis and Immunity (see also, Memorial Sloan Kettering Cancer Center, The Rockefeller University, and Hospital for Special Surgery)

2315 Broadway
New York, NY 10024
Telephone: 212-345-2382 or 212-456-6102

- Mercedes Castiel, MD, Gynecology
  Telephone: 646-962-2110
  Email: mec9109@med.cornell.edu

Services Offered:
Gynecological cancer evaluation and treatment.

Ann Van Heest, MD, Professor

- University of Minnesota, Department of Orthopaedic Surgery
  2450 Riverside Avenue, Rm R200
  Minneapolis, MN 55454
  Telephone 612-273-8086
  Email: vanhe003@umn.edu

- Gillette Children’s Specialty Healthcare
  200 University Avenue East
  St. Paul, MN 55101
  Telephone: 651-291-2848

- Shriners Hospital for Children, Twin Cities Unit
  2025 East River Parkway
  Minneapolis, MN 55414
  Telephone: 612-596-6100

Services Offered:
- Hand and upper extremity surgery in the pediatric population.

Cincinnati Children’s Hospital Medical Center

Fanconi Anemia Comprehensive Care Center

3333 Burnet Avenue
Cincinnati, OH 45229

- Roger Cornwall, MD, Associate Professor of Pediatrics, Division of Orthopaedics (Hand Surgery)
  Telephone: 513-803-HAND Fax: 513-636-3928
  Email: roger.cornwall@chmc.org

HAND SURGEONS
Hospital for Special Surgery
Part of New York Consortium for Inborn Errors of Hematopoiesis and Immunity (see also, Memorial Sloan Kettering Cancer Center, The Rockefeller University, and The New York Presbyterian Hospital)
535 E 70th Street, 5th Floor
New York, NY 10065
- Aaron Daluiski, MD, Orthopedics – Hand and Upper Extremity Surgery, Lerners Children’s Pavilion
  Telephone: 212-606-1284

University of Virginia Health System
- A. Bobby Chhabra, MD, Professor and Chair Department of Orthopaedic Surgery
  Lillian T. Pratt Distinguished Professor of Orthopaedic Surgery
  Professor of Plastic and Reconstructive Surgery
  Telephone: 434-243-0218 Fax: 434-243-0290
  Appointments: 434-982-4263
  Email: AC2H@hscmail.mcc.virginia.edu

Shriners Hospital for Children
3551 North Broad Street
Philadelphia, PA 19140
- Scott Kozin, MD, Chief of Staff, Shriners Hospital for Children Philadelphia, Professor, Orthopedic Surgery, Temple University
  Telephone: (215) 430-4034
  Email: skozin@shrinenet.org
- Linda Filipone, Nurse Coordinator
  Telephone: (215) 430-4074
  Email: lfilipone@shrinenet.org
- Maureen Fulcher, Nurse Assistant
  Telephone: (215) 430-4204
  Email: mfulcher@shrinenet.org

Services Offered:
- Evaluation and treatment of FA children with upper limb and other orthopedic problems;
- Surgical expertise in hand and upper limb differences;
- Occupational therapy evaluation and treatment, including splints, adaptive equipment, and other needs.

Boston Foundation for Sight
464 Hillside Avenue, Suite 205
Needham, MA 02494
www.bostonsight.org

- Gillian Fontana, New Patient Affairs Coordinator
  Telephone: 781-726-7501 Fax: 781-726-7310
  Email: GFontana@bostonsight.org

Services Offered:
BostonSight® PROSE treatment is a process by which visual function is restored to a patient with complex corneal disease, enabling them to reclaim their life. During PROSE treatment, doctors customize prosthetic devices to replace or support impaired ocular surface functions, improving vision and reducing pain and light sensitivity.

Boston Foundation for Sight is a non-profit organization with a mission to improve the quality of life for patients and their families by transforming the understanding, treatment, and care of complex corneal disease.
Cincinnati Children’s Hospital Medical Center
Fanconi Anemia Comprehensive Care Center
3333 Burnet Avenue
Cincinnati, OH 45229

- **Michael Rutter, MD**, Professor of Pediatrics, Division of Otolaryngology
  Telephone: 513-636-4356 Fax: 513-636-8133
  Email: mike.rutter@cchmc.org

Cornell University, Weill Medical College
Department of Otolaryngology-Head and Neck Surgery
1305 York Avenue, 5th Floor
New York, NY 10021

- **David Kutler, MD**, Associate Professor
  Telephone: 646-962-4323
  Email: dik2002@med.cornell.edu

Clinical Interests: Head and neck cancer in Fanconi anemia patients, tongue cancer, disorder of nasal sinus, skull base surgery, pharynx, thyroid cancer, benign tumor of oral cavity, thyroid surgery, head and neck cancer surgery, and salivary disorder.

Johns Hopkins Medical Institutions
601 N. Caroline Street, 6th Floor
Baltimore, MD 21287-0910

- **Joseph Califano, MD**, Professor, Otolaryngology, Head & Neck Surgery & Head & Neck Research Division
  Telephone: 410-955-6420 Fax: 410-955-8510
  Email: jcalifa@jhmi.edu

Clinical Interests: Tumors of the oral cavity, larynx, pharynx, neck, skull base, salivary glands, thyroid cancer, premalignant conditions of the upper aerodigestive tract, and unknown primary head and neck squamous cell carcinoma, skin cancer and melanoma.

Memorial Sloan-Kettering Cancer Center
1275 York Avenue
New York, NY 10021

- **Bhuvanesh Singh, MD, PhD**, Head and Neck Cancer
  Telephone: 212-639-2024
  Email: singhb@mskcc.org

Clinical Interests: All head and neck cancers, with a particular focus on cancers of the mouth (tongue, floor of mouth, and buccal mucosa), skull base, and salivary and thyroid glands, as well as melanomas and skin cancers of the head and neck region.

National Institutes of Health
NIDCD/NIH
10 Center Drive, Building 10
Bethesda, MD 20892

- **H. Jeffrey Kim, MD**, Senior Staff Clinician, Head and Neck Surgery Branch, National Institute on Deafness and Other Communication Disorders
  Professor, Department of Otolaryngology, Head and Neck Surgery, Georgetown University Hospital
  Telephone: 301-496-5369 Fax: 301-402-0409
  Email: kimj@niddc.nih.gov

Clinical Interests: Dizziness, hereditary hearing loss, balance disorders, acoustic neuroma and skull base surgery, otosclerosis, cholesteatoma.

- **Carter Van Waes, MD, PhD**, Chief Head and Neck Surgery Branch; Clinical Director, National Institute on Deafness and other Communication Disorders
  Telephone: 301-402-4216 Fax: 301-402-1140
  Email: vanwaes@niddc.nih.gov

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

University of California at San Francisco
CTSI, Box 0558
550 16th Street, 6th Floor
San Francisco, CA 94158-2549

- **Jennifer Rubin Grandis, MD, FACS**
  Telephone: 415-514-8084
  Email: Jennifer.Grandis@ucsf.edu

Specialty: Otolaryngology
Sub Specialty: Head and neck surgery

University of Chicago
5841 S. Maryland Avenue, MC6092
Chicago, IL 60634

- **Everett Vokes, MD**, John E. Ultmann Professor, Chairman, Department of Medicine, Physician-in-Chief, University of Chicago Medicine and Biological Sciences
  Telephone: 773-702-9306 Fax: 773-702-4427
  Email: evokes@medicine.bsd.uchicago.edu

Clinical Interests: Hematology, oncology, head and neck cancer, and lung cancer.
• Tanguy Seiwert, MD. Assistant Professor of Medicine  
  Telephone: 773-702-2452  Fax: 773-702-3002

Clinical Interests: Head and neck cancer and lung cancer.

University of Cincinnati, College of Medicine
Department of Otolaryngology  
P.O. Box 670528  
Cincinnati, OH 45267

• Keith A. Casper, MD, Assistant Professor  
  Telephone: 513-475-8400  Fax: 513-558-4477  
  Email: Keith.casper@uc.edu

• Keith M. Wilson, MD
• Lee A. Zimmer, MD

University of Minnesota
Fanconi Anemia Comprehensive Care Program
University of Minnesota Medical Center and  
Masonic Children's Hospital
MMC 396, University of Minnesota  
420 Delaware Street, SE  
Minneapolis, MN 55455

• Frank Ondrey, MD, PhD, FACS, Associate Professor of Otolaryngology, Director, Molecular Oncology Program  
  Telephone: 612-624-5900  
  Email: ondre002@umn.edu

Clinical Interests: Head and neck cancer, precancerous mouth and throat lesions, comprehensive general otolaryngology, and facial trauma.

University of Texas Health Science Center at Houston
Department of Otorhinolaryngology - Head & Neck Surgery  
6400 Fannin, Suite 2700  
Houston, TX 77030

• Ron J. Karni, MD. Assistant Professor of Otolaryngology, Assistant Professor of Medical Oncology  
  Telephone: 713-486-5000 and 713-500-5410  
  Email: ron.j.karni@uth.tmc.edu

Clinical Interest: Head and neck cancer, robotic, and minimally-invasive surgery of the head and neck.

Services Offered: Management of head and neck cancer including surgery, chemotherapy, and radiation oncology.

University of Texas MD Anderson Cancer Center
1515 Holcombe Boulevard, Unit 1445  
Houston, TX 77030

• Erich Madison Sturgis, MD, MPH, FACS, Professor of Surgery, Professor of Epidemiology  
  Telephone: 713-792-5432  Fax: 713-794-4662

Clinical Interests: Head and neck cancer, salivary carcinoma, and thyroid cancer, human papillomavirus, and sarcomas of the head and neck.

Services Offered: Multi-disciplinary evaluation and treatment of head and neck tumors.
PRE-IMPLANTATION GENETIC DIAGNOSIS

Genesis Genetics
705 S. Main Street
Plymouth, MI 48170
www.genesisgenetics.org

• John Kitchen, PhD
  Telephone: 313-579-9650  Fax: 313-544-4006

• Elizabeth Cameron, MS, CGC, Certified Genetic Counselor
  Telephone: 313-579-9650  Fax: 313-544-4006
  Email: counselor@genesisgenetics.org

• Jeannie Klavanian, MS, Genetic Counselor
  Telephone: 313-579-9650  Fax: 313-544-4006

Services Offered:
- Pre-pregnancy/pre-implantation diagnosis for Fanconia anemia (including types A, C, D2, F, G, I, and J, among others). Helping a couple begin a pregnancy knowing their baby will not have Fanconi anemia.
- Extensive experience in Fanconi anemia mutation testing with HLA identity matching for families desiring a healthy baby and cord blood stem cells that are a perfect match to their Fanconi anemia-affected child needing stem cell transplantation.
- Personalized treatment regimens coordinated with the family’s hematologist, geneticist, obstetrician, and (if necessary) transplantation doctors. The FA family does not need to travel for these PGD services. Our clinic collaborates with the leading molecular biologists in Fanconi anemia research, with over 230 in vitro fertilization programs, and with internationally respected Fanconi anemia transplantation experts.

Reproductive Genetic Innovation
2910 MacArthur Boulevard
Northbrook, IL 60062
Telephone: 847-400-1515
www.rgipgd.com
Email: info@rgipgd.com

• Stephanie Peters, MGC, CGC
• Divya Shah, MS, LCGC
• Agnes Machaj, MS

Services Offered:
- Pre-implantation genetic diagnosis for any known Fanconi anemia mutations with or without HLA matching for sibling bone marrow donation;
- Pioneers in PGD; first laboratory in the world to successfully perform PGD for FA and HLA matching. Highly accurate state-of-the-art testing methods;
- Able to test for chromosomal abnormalities in addition to FA and HLA on a single cell from an embryo;
- Free consultations with genetic counselors (in-person or via telephone);
- Travel to our facility is not necessary as we collaborate with hundreds of in vitro fertilization clinics all over the world.

RADIATION ONCOLOGY

University of Pittsburgh Cancer Institute
UPMC Cancer Pavilion, POB 2
5150 Centre Avenue
Pittsburgh, PA 15232

• Joel Greenberger, MD
  Telephone: 412-647-3602
  Email: greenbergerjs@upmc.edu

Clinical Interests:
- Radiation sensitivity in Fanconi anemia

Services Offered:
- Consultation (telephone, email, in person) with families and physicians regarding the use of radiation in a person with Fanconi anemia.
- Treat patients diagnosed with cancer by utilizing various forms of radiation therapy.
U.S. Fanconi Anemia Testing Resources
# U.S. Fanconi Anemia Testing Resources

<table>
<thead>
<tr>
<th>Institution</th>
<th>Test</th>
</tr>
</thead>
</table>
| Cincinnati Children’s Hospital Medical Center  
Fanconi Anemia Comprehensive Care Center Bone Marrow Failure Clinic  
Cincinnati, OH  
Erica L. Goodridge, RN, BSN, CPN  
Care Manager, Fanconi Anemia Comprehensive Care Center  
513-636-3218  
Toll-free: 1-800-344-2462, ext. 3218  
erica.goodridge@cchmc.org | DEB/MMC diagnostic testing using blood or bone marrow samples.  
Complementation analysis for $A, B, C, E, F, G, L, I$ (I analysis via skin testing only) and FANCD2 (via western blot). Testing done with blood, skin biopsy or amniocytes. Note: This testing must be requested by clinicians or researchers.  
Molecular testing to find specific mutations for patients with $FANCA$, $FANCC$, or $FANCG$.  
Prenatal diagnostic molecular testing for $FANCA$, $FANCC$, or $FANCG$.  
Carrier detection testing for patients with a family history of FA, from complementation groups $FANCA$, $FANCC$, or $FANCG$. |
| Dana-Farber Cancer Institute  
Boston, MA  
Alan D’Andrea, MD  
617-632-2080  
alan_dandrea@dfci.harvard.edu  
Lisa Moreau, MS  
617-632-6302  
lisa_moreau@dfci.harvard.edu | DEB/MMC diagnostic testing using blood, bone marrow, or skin fibroblasts.  
FANCD2 western blot (Research).  
FA carrier testing. |
| Indiana University School of Medicine  
Wells Center, Riley Hospital for Children  
Indianapolis, IN  
Helmut Hanenberg, MD  
317-278-9290 or 274-2980  
Fax 317-274-2852  
hhanenbe@iupui.edu | Complementation Group (Research):  
Use of retroviruses for $A, B, C, D1, D2, E, F, G, I, J, L, M, N, O, P, Q$ in primary T-cells, bone marrow cells, or fibroblast cells or in lymphoblast cell lines (LCL) (Research).  
FANCD2 western blotting (research). |
| Indiana University School of Medicine  
Cytogenetic Lab, Dept. of Medical & Molecular Genetics  
Indianapolis, IN  
Gail H. Vance, MD  
317-274-2243/317-278-0172  
Fax 317-278-1616  
ghvance@iupui.edu | Diagnostic testing: Cytogenetic breakage studies with DEB on peripheral blood and fibroblast specimens.  
Mutation testing for $FANCA$, $FANCC$, and $FANCG$. Collaborative mutation testing and research with Gail Vance, MD, and Shaochun Bai, PhD, Medical & Molecular Genetics, Indianapolis, IN. |
<table>
<thead>
<tr>
<th>Institution</th>
<th>Test</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Oregon Health &amp; Science University</strong>&lt;br&gt;Portland, OR&lt;br&gt;Susan Olson, PhD, FACMG (cytogenics)&lt;br&gt;503-494-5964&lt;br&gt;<a href="mailto:olsonsu@ohsu.edu">olsonsu@ohsu.edu</a>&lt;br&gt;C. Sue Richards, PhD, FACMG (molecular)&lt;br&gt;503-494-5400&lt;br&gt;<a href="mailto:richarsu@ohsu.edu">richarsu@ohsu.edu</a></td>
<td>DEB/MMC diagnostic testing - blood and skin fibroblasts.&lt;br&gt;Next-Generation sequencing comprehensive Fanconi panel is now available for all FANC genes. Exon-centric microarray is also available for detection of deletions and duplications in all FANC genes.&lt;br&gt;Complementation and full gene mutation analysis by Sanger sequencing for A, C, G, E, F as well as targeted sequencing of any exon is available. Deletion/duplication analysis for FANCA is also available by MLPA. Prenatal testing available for known mutations. Custom sequencing for known mutations in Fanconi genes other than A, C, G, E, F is also available. Please see GeneTests for further information.&lt;br&gt;FA carrier testing.</td>
</tr>
<tr>
<td><strong>Prevention Genetics</strong>&lt;br&gt;3700 Downwind Drive&lt;br Marshfield, WI 54449&lt;br&gt;Michael Chicka. PhD&lt;br&gt;715-387-0484&lt;br&gt;<a href="mailto:michael.chicka@preventiongenetics.com">michael.chicka@preventiongenetics.com</a></td>
<td>FA gene sequencing and deletion/duplication analysis for molecular diagnosis. Genes analyzed (at press): FANCA, FANCB, FANCC, FANCD2, FANCE, FANCF, FANCG, FANCI, FANCJ/BRIP1, FANCL, FANCM, FANCN/PALB2, FANCO/RAD51C, FANCP/SLX4, FANCP/ERCC4&lt;br&gt;Tests offered include:&lt;br&gt;• Next-Generation and Sanger Sequencing FA Panels for identifying the particular FA gene and variant(s) of interest;&lt;br&gt;• Sanger sequencing of individual FA genes when gene of interest is known;&lt;br&gt;• Sanger confirmation of all pathogenic variants and variants of unknown significance found by Next-Generation Sequencing;&lt;br&gt;• Detection of large deletions/duplications using custom designed, high-density, gene-centric array CGH technologies;&lt;br&gt;• Targeted variant analysis for familial variants and for confirming research findings;&lt;br&gt;• Prenatal testing.</td>
</tr>
<tr>
<td><strong>Quest Diagnostics</strong>&lt;br&gt;Chantilly, VA&lt;br&gt;Dr. Steven Schonberg&lt;br&gt;800-336-3718 x7285&lt;br&gt;</td>
<td>DEB diagnostic testing performed on blood, bone marrow, and skin fibroblasts (in addition to prenatal testing): the doctor needs to specify DEB test, otherwise it is possible that a DNA carrier test for FANCC may be done.&lt;br&gt;Mutation analysis for FANCC (IVS4+4A&gt;T and 322delG).&lt;br&gt;Prenatal diagnosis.</td>
</tr>
<tr>
<td><strong>Quest Diagnostics</strong>&lt;br&gt;San Juan Capistrano, CA&lt;br&gt;Joy Redman, MS, MBA, CGC&lt;br&gt;800-642-4657, ext. 4279&lt;br&gt;<a href="mailto:Joy.B.Redman@questdiagnostics.com">Joy.B.Redman@questdiagnostics.com</a></td>
<td></td>
</tr>
</tbody>
</table>
U.S. Fanconi Anemia Testing Resources

<table>
<thead>
<tr>
<th>Institution</th>
<th>Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>University of Minnesota Physicians Outreach Laboratories Minneapolis MN</td>
<td>Next Generation sequencing. These methods will detect point mutations and small indel mutations (&lt;18bp).</td>
</tr>
<tr>
<td>Bharat Thyagarajan, MD, PhD, Director Matt Bower, MS, CGC, Contact 612-624-8948 <a href="mailto:mbower1@fairview.org">mbower1@fairview.org</a></td>
<td>Copy number analysis for large deletions/duplications is under development and will be available in 2015.</td>
</tr>
<tr>
<td></td>
<td>Targeted mutation analysis available in families with known mutations. Lab requires a positive control to develop primers.</td>
</tr>
<tr>
<td></td>
<td>Complementation and analyze genes: FANCA, FANCB, FANCC, FANCD1, FANCD2, FANCE, FANCF, FANCG, FANCI, FANJ (BRIP1), FANCL, FANCM, FANCN (PALB2), FANCO (RAD51C), FANCP (SLX4), FANQ (ERCC4).</td>
</tr>
</tbody>
</table>

Please note:
- The laboratories listed are CLIA (Clinical Laboratories Improvement Amendments)-certified.
- Estimated costs for diagnostic tests range from approximately $1,000 - $1,200. Check with your insurance company for coverage. The average turnaround time for testing results is about 10 working days. For more information, please contact the labs directly.
- Additional testing information for Fanconi anemia is available at: [http://geneclinics.org](http://geneclinics.org).
  - Select “Gene Reviews”.
  - Select “Search by Disease”.
  - Enter “Fanconi anemia” into the text box.
- “Research” indicates that the results will be used for research purposes only and may not be shared with referring physician/family.
International Fanconi Anemia
Treatment Resources

Editors’ note and disclaimer: The resource list provided in this guide is not comprehensive. Inclusion on the list does not imply endorsement by the Fanconi Anemia Research Fund, Inc. Families are encouraged to ask clinicians about their experience treating patients with Fanconi anemia.

AUSTRALIA

The Children’s Hospital at Westmead
Sydney, NSW 2145, Australia
www.chw.edu.au/prof/services/fanconi_anaemia

- Dr. Julie Curtin, MD, PhD, Head Haematology Department
  Telephone: 612-9845-0000  Fax 612-9845-3332
  Email: julie.curtin@health.nsw.gov.au

- Professor Peter Shaw, Head BMT Service
  Telephone: 612-9845-0000 Fax: 612-9845-2171
  Email: peter.shaw@health.nsw.gov.au

- Ida O’Brien, Clinical Nurse Consultant BMT Follow Up
  Telephone: 612- 9845-0000  Fax: 612-9845-2171
  Email: Ida.obrien@health.nsw.gov.au

- A/Prof. Meredith Wilson, Clinical Geneticist
  Telephone: 612-9845-3273 Fax: 612-9845-3204
  Email: meredithwilson@health.nsw.gov.au

- A/Prof. David Little, Director Orthopaedic Research
  Telephone: 612-9845-3352 Fax: 612-9845-3180
  Email: david.little@health.nsw.gov.au

- Professor Chris Cowell, Head Endocrinology Department
  Telephone: 612-9845-0000  Fax: 612-9845-3170
  Email: chris.cowell@health.nsw.gov.au

- Dr. Carsten E. Palme, FRACS, Surgeon, Otolaryngology Head & Neck Surgery
  Telephone: 612-9845-6025 Fax: 612-9893-7440
  Email: Carsten_Palme@specialistservices.com.au

- Mark Schifter, Oral Medicine and Oral Pathology
  Telephone: 612-9845-8716 Fax: 612-9845-5740
  Email: mark.schifter@swahs.health.nsw.gov.au

Services Offered:
This 350-bed tertiary care paediatric institution provides comprehensive care for the majority of children in NSW with all diagnoses. This includes a comprehensive team of medical professionals working in disease-specific multi-disciplinary teams to manage complex disorders with multi-system manifestations, such as Fanconi anaemia. We offer comprehensive management of new and previously diagnosed FA patients, including:

- Diagnostic testing and screening of siblings;
- Genetic counseling; coordination of gene testing via overseas facilities to identify causative mutations in affected individuals; discussion of family planning options for future pregnancies, including prenatal diagnosis or pre-implantation genetic diagnosis for families with identified mutations;
- Orthopaedic management, including specialist hand, upper limb and congenital hand clinic;
- Haematological management;
- Blood and marrow transplantation: comprehensive program of related, unrelated and haploidentical marrow, PBSC and cord blood transplant;
- Co-ordinated long-term follow-up and ongoing surveillance, with particular reference to BMT follow-up, oral, head and neck cancer screening and endocrine follow-up (Chris Cowell);
- Translational research on non-radiotherapy-based BMT conditioning including a well-established drug pharmacokinetic laboratory for real time tailoring of drug doses in individual patients.

Princess Margaret Hospital for Children
Roberts Road Subiaco
Perth, Western Australia 6008, Australia

- Catherine Cole, MBBS, FRACP, FRCPA, Clinical Director of Bone Marrow Transplantation Program

- Tina Carter, FRACP, PhD, Bone Marrow Transplant Physician
  Telephone: 08-9340-8222
  Email: Tina.Carter@health.wa.gov.au

- Shanti Ramachandran, MBBS, FRACP, MPaeds, Paediatric Oncologist-Clinical Haematologist
  Telephone: 08-9340-8222
  Email: Shanti.Ramachandran@health.wa.gov.au
Sydney Children’s Hospital
Blood & Marrow Transplant Program
Kids Cancer Centre
Sydney Children’s Hospital
High St, Randwick
Sydney, NSW, 2031, Australia

- **A/Prof Tracey O’Brien**, Director, Blood and Marrow Transplant Program, Deputy Director and Head of Clinical Service, Kids Cancer Centre
  Telephone: 02-93821733  Fax: 02-93821789
  Email: tobrien@unsw.edu.au

- **Dr. Susan Russell**, Head Haematology, Kids Cancer Centre
  Telephone: 02-93821733  Fax: 02-93821789
  Email: Susan.Russell@sesiahs.health.nsw.gov.au

- **A/Prof. Richard Cohn**, Head, Oncology, Kids Cancer Centre
  Telephone: 02-93821731  Fax: 02-93821789
  Email: Richard.Cohn@sesiahs.health.nsw.gov.au

- **Anne Senner**, BMT Coordinator, Blood and Marrow Transplant Program, Kids Cancer Centre
  Telephone: 02-93821733  Fax: 02-93821789
  Email: Anne.Senner@sesiahs.health.nsw.gov.au

- **Lucy Maurice**, BMT Clinical Nurse Consultant, Blood and Marrow Transplant Program, Centre for Children’s Cancer and Blood Disorders
  Telephone: 02-93821655
  Email: Lucy.Maurice@sesiahs.health.nsw.gov.au

Services Offered:
Sydney Children’s Hospital is a large tertiary paediatric hospital with comprehensive multi-disciplinary services. We offer evaluation of new and previously diagnosed patients with specialists in haematology, bone marrow transplantation, genetics, endocrinology, nephrology, surgery and adolescent medicine. We offer on-site DEB testing, facilitation of DNA mutation testing, family genetic screening and referral for pre-implantation genetic diagnosis. In addition, comprehensive social work, psychology, family support networks are available. The transplant program is one of the oldest and largest national programs with over 900 transplants performed since establishment of the in 1975. The centre is a national leader in unrelated marrow and cord transplants with particular interest in transplant for non-malignant diseases. The program offers a well established multi-disciplinary comprehensive pre- and post-transplant service for patients with FA. The centre director has specialized knowledge in FA having trained in a leading U.S. FA transplant centre, and the centre collaborates with the International Fanconi Anemia Registry (Dr. Arleen Auerbach).

AUSTRIA

**St. Anna Children’s Hospital**
Department of Hematology and Oncology
Kinderspitalgasse 6
Vienna A - 1090, Austria

- **Prof. Wolfgang Holter**, Medical Director
  Email: aerztliche.direktion@stanna.at

Services Offered:
- Stem cell transplants for FA patients.

BRAZIL

**Hospital de Clinicas, University of Parana**
Servício de Transplante de Medula Óssea - 15º andar
Rua General Carneiro, 181 - 15º andar
80060-900-Curitiba-PR, Brazil

- **Carmem Bonfim, MD**, Director of Pediatric Stem Cell Transplant Program, Stem Cell Transplant in Genetic Diseases, Coordinator, Fanconi Anemia Outpatient Clinic
  Telephone: 55-41-3360-1000  Fax 55-41-3360-1015
  Email: carmembonfim@gmail.com

- **Ricardo Pasquini, MD, PhD**, Senior Professor
  Federal University of Parana
  Telephone: 55-41-3360-1000  Fax: 55-41-3360-1015
  Email: pasquini@hc.ufpr.br

Services Offered:
- Comprehensive clinic for FA patients;
- Out-patient unit for diagnostic procedures and treatment;
- Cytogenetics laboratory performing DEB chromosomal breakage testing and conventional cytogenetics of bone marrow;
- Transplant unit performing related and unrelated bone marrow and umbilical cord transplants;
- Haploidentical transplants;
- Mutation analysis (FANCA, C and G) and FANCD2 by western blot.
CANADA

Hospital for Sick Children
University of Toronto
555 University Avenue
Toronto, Ontario, Canada M5G 1X8

- Yigal Dror, MD, FRCP(C), Professor of Paediatrics; Director, Marrow Failure and Myelodysplasia Program; Head, Hematology Section; Division of Hematology/Oncology; Scientist, Program in Genetics and Genome Biology, Research Institute
  Telephone: 416-813-5668  Fax: 416-813-5327
  Email: yigal.dror@sickkids.ca

- Adam Gassas, MBChB, MSc, MRCP, DCH, MRCPCH, Associate Professor of Pediatrics; Section of Blood & Marrow Transplant, Division of Hematology/Oncology
  Telephone: 416-813-8227  Fax: 416-813-5327
  Email: adam.gassas@sickkids.ca

Princess Margaret Hospital
Ontario Cancer Institute
University of Toronto
610 University Avenue
Toronto, Ontario, M5G 2M9, Canada

- Jeffrey H. Lipton, FRCPC, MD, PhD, Leukemia and Allogeneic Stem Cell Transplant Programs, PMH Professor of Medicine, University of Toronto
  Telephone: 416-946-2266  Fax: 416-946-6585
  Email: Jeff.Lipton@uhn.on.ca

University of Manitoba
ON2021a-675 McDermot Avenue
Winnipeg, Manitoba, Canada R3E 0V9

- John J. Doyle, MD, FRCPC, FAAP, Associate Professor, Dept. of Pediatrics and Child Health, University of Manitoba; Head, Pediatric Hematology/Oncology/BMT
  Telephone: 204-787-4135  Fax: 204-786-0195
  Email: john.doyle@cancercare.mb.ca

CHINA

Tianjin First Central Hospital
No. 24, Fukang Road, Nankai District, Tianjin, China

Mingfeng Zhao, MD, PhD

Capital Institute of Pediatrics
No. 2 Yabao Road
Chaoyang District
100020 Beijing, China

Xiaodong Shi, MD, PhD
Telephone: 13911601076

COLOMBIA

Clinica Las Americas
Diagonal 75 B #2 A80 Ofic. 520
Medellin
Antioquia, Colombia

- Dr. Amado Karduss, Adult Hematology/Stem Cell Transplantation
  Telephone: 57 4 3409314
  Email: amaka@une.net.co

- Dr. Yadira Coll, Pediatric Hematology
  Telephone: 57 4 3409314
  Email: yacoll@une.net.co

Services Offered:
- Evaluation;
- Medical treatment;
- FA stem cell transplantation.

Dr. Adriana Linares
Hospital de La Misericordia
Av Caracas 1-67
Pediatric Hematology/Oncology Unit
Telephone: 571-381-1970 extension 1309
Email: alinaresb@gmail.com

- Universidad Nacional de Colombia
  Departamento de Pediatría
  Unidad de Oncohematologíe PEDIATRICA
  Av Caracas 1-67 4 piso
  Bogotá, Colombia
Services Offered:
- Pediatric hematology oncology, clinical evaluation, medical treatment, and therapy.

Centro Médico Imbanaco de Cali
Bone Marrow Transplant Unit
Carrera 38 A No. 5A 100
Cali, Valle, Colombia

- Oscar W. Ramirez, MD, MPhil
  Telephone: 572-682-1000 or 572-518-6000
  Email: oscar.ramirez@imbanaco.com.co or oramirez1167@gmail.com

CZECH REPUBLIC

University Hospital Motol
Department of Paediatric Haematology and Oncology V
Uvalu, 84
150 06 Prague, Czech Republic

- Prof. Petr Sedlacek
  Telephone: 420 2 2443 6552 Fax: 420 2 2443 6519
  Email: petr.sedlacek@fmotol.cuni.cz

Services Offered:
- Stem cell transplants for FA patients.

DENMARK

University Hospital of Aarhus at Skejby
Brendstrupgaardsvej 100
DK-8200 Aarhus N, Denmark

- Niels Clausen, MD, Department of Pediatrics
  Telephone: 45-7845-1673
  Email: niecla@rm.dk

Services Offered:
- Diagnosis, treatment and follow-up for children with Fanconi anemia.

FRANCE

Hôpital Robert Debré
48, boulevard Sérurier
75935 Paris cedex 19, France

- Thierry Leblanc, MD, Department of Pediatric Hematology
  Secretary: 33-1-7128-2535 Fax: 33-1-4003-4740
  Email: thierry.leblanc@rdb.aphp.fr

- Jean-Hugues Dalle, MD, PhD, Department of Pediatric Hematology
  Telephone direct: 33-1-4003-1241
  Secretary: 33-1-4003-5388 Fax: 33-1-4003-4740
  Email: jean-hugues.dalle@rdb.aphp.fr

Services Offered (primarily for children):
- Bone marrow, peripheral stem cell and cord blood transplants;
- FA diagnosis: breakage tests, cell cycle, FANCD2 analysis, mosaicism on skin biopsy, retroviral group complementation, bone marrow karyotype (Dr. Jean Soulier);
- Gene sequencing on grouped patients, in collaboration with Institut Curie (Pr. Dominique Stoppa-Lyonnet);
- Head and neck cancer evaluation and treatment (Dr. Francis Pascal and Dr. Arnaud Rigolet);
- Cell therapy laboratory (Dr. Jerome Larghero);
- Gene therapy laboratory (Dr. Philippe Leboulch).

Hôpital Saint-Louis
1, Avenue Claude Vellefaux
75010 Paris, France

- Gérard Socié, MD, PhD, Department of Hematology Transplantation
  Telephone direct: 33-1-4249-9824
  Secretary: 33-1-4249-9639 Fax: 33-1-4249-9636
  Email: gerard.socie@sls.aphp.fr

- Jean Soulier, MD, PhD, Genome Rearrangements and Cancer Group, Hematology Laboratory
  Telephone: 33-1-4249-9891 Fax: 33-1-4249-4027
  Email: jean.soulier@sls.aphp.fr

- Arnaud Rigolet, MD, Department of Oral and Maxillofacial Surgery
  Email: arnaud.rigolet@sls.aphp.fr

Services Offered (primarily for teens and adults):
- Bone marrow, peripheral stem cell and cord blood transplants;
- FA diagnosis: breakage tests, cell cycle, FANCD2
analysis, mosaicism on skin biopsy, retroviral group complementation, bone marrow karyotype (Dr. Jean Soulier);
- Gene sequencing on grouped patients, in collaboration with Institut Curie (Pr. Dominique Stoppa-Lyonnet);
- Head and neck cancer evaluation and treatment (Dr. Francis Pascal and Dr. Arnaud Rigolet);
- Cell therapy laboratory (Dr. Jerome Larghero);
- Gene therapy laboratory (Dr. Philippe Leboulch).

GERMANY

Charité, Campus Virchow Klinikum
University Medicine, Berlin
Children’s Hospital
Augustenburger Platz 1
13353, Berlin, Germany
- Jörn-Sven Kühl, MD
  Telephone: 49-30-450 566432
  Fax: 049-030-450-566919
  Email: jskuehl@charite.de

Services Offered:
- Pediatric bone marrow transplant service;
- Stem cell laboratory;
- Stem cell bank;
- Cytogenetic laboratory;
- German Fanconi anemia registry.

Hannover Medical School
Department of Pediatric Hematology and Oncology
Carl-Neuberg-Str. 1
30625 Hannover, Germany

Christian Peter Kratz, MD, Director
Telephone: 49 (0)511 532 6711  Fax: 49 (0)511 532 9120
Email: kratz.christian@mh-hannover.de

Services Offered:
- Natural history study for patients with Fanconi anemia;
- Guidance in clinical decision making.

Heinrich Heine University Medical Center
Children’s Hospital
Moorenstrasse 5
40225 Düsseldorf, Germany

- Eunike Velleuer, MD, Department of Pediatric Hematology, Oncology, and Clinical Immunology
  Telephone: 49-211-811-7687  Fax: 49-211-811-7634
  Email: velleuer@uni-duesseldorf.de

- Arndt Borkhardt, MD, Director, Department of Pediatric Hematology, Oncology, and Clinical Immunology
  Telephone: 49-211-811-7680  Fax: 49-211-811-6206
  Email: lesch@med.uni-duesseldorf.de

Services Offered:
- Clinical care of FA patients;
- Cooperation with Ralf Dietrich, German FA family support group (Deutsche FA-Hilfe e.V.) on “Reducing the burden of squamous cell carcinoma in Fanconi anemia;”
- Cooperation with Birgit Henrich, University of Duesseldorf, Microbiology; Microbiom of the oral cavity in FA;
- Cooperation with Ruud Brakenhoff, University of Amsterdam, on “Progression of FA-SCC and Development of a Non-Invasive Screening Method for Precursor Lesions;”
- Cooperation with Prof. Stefan Biesterfeld, University of Duesseldorf, Cytopathology; non-invasive testing of oral lesions (Cytology, DNA-Cytometry);
- Cooperation with Prof. Torsten Remmerbach, University of Leipzig, development of alternative non-invasive methods for the detection of oral cancers.

University of Tuebingen
Children’s University Hospital
Department of Hematology/Oncology and General Pediatrics
Hoppe-Seyler-Strasse 1
72076 Tuebingen, Germany

- Prof. Rupert Handgretinger, MD, Chairman
  Telephone: 49-7071-298-4744  Fax: 49-7071-294713
  Email: Rupert.Handgretinger@med.uni-tuebingen.de

Services Offered:
- Evaluation of new patients;
- Hematopoietic stem cell transplantation from HLA-matched siblings, matched unrelated donors and haploidentical family donors;
- Co-transplantation of bone marrow with mesenchymal stem cells to enhance engraftment and to prevent graft-versus-host-disease (GvHD);
- Extracorporal photopheresis in small children for the prevention and treatment of GvHD;
- Adoptive transfer of virus-specific T-cells to prevent viral infections post-transplant;
- Long-term follow-up studies (growth, endocrinology, quality of life).
**INDIA**

**Apollo Specialty Hospital**
320 Padma Complex
Anna Salai
Chennai 600 035, India

- **Sheila Mohan, MBBS, DCH, PhD**
  Telephone: 91-44-2491-2943
  Mobile: 91-92-8211-4661

- **Revathi Raj, MBBS, DCH, MRCP (Path)**
  Telephone: 00-91-44-33151294

**Services Offered:**
- 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;
- Diagnostic testing (MMC test) and screenings of siblings;
- Complementation grouping;
- Genetic counseling;
- Stem cell transplantation;
- Maintenance of national database: Registry for Fanconi Anemia in India (REFAIN).

**National Institute of Immunohaematology (ICMR)**
13th floor, New Multistoried Building
K.E.M. Hospital Campus, Parel
Mumbai 400012, India

- **Dr. V. Babu Rao**
  Telephone: 91-22-24138518 or 24138519
  Fax: 91-22-24138521
  Email: vbaburao@hotmail.com

**Services Offered:**
- Chromosomal breakage study using MMC and DEB test;
- Cytogenetic study from bone marrow and FISH analysis;
- FANCD2 western blot;
- Molecular testing of complementation groups FANCA, FANCC, FANCG;
- Prenatal diagnosis of FA after mutation detection in proband.

**IRAN**

**Tehran University of Medical Sciences**
Shariati Hospital
Hematology-Oncology and SCT Research Center
Kargar Avenue
14114, Tehran, Iran

- **Ardeshir Ghavamzadeh, MD, Professor of Medicine**
  Adult Hematologist Oncologist
  President of Hematology-Oncology and SCT Research Center
  Telephone: 98-21-84902635 Fax: 98-21-88004140
  Email: ghavamza@sina.tums.ac.ir

- **Amir Ali Hamidieh, MD, Associate Professor of Medicine**
  Pediatric Hematologist Oncologist
  Director of Fanconi Anemia Transplant Program
  Telephone: 98-21-84902645 Fax: 98-21-88004140
  Email: aahamidieh@sina.tums.ac.ir

**Services Offered:**
- Pediatric and adult FA patients can be seen by specialists in pediatric and adult medicine;
- Pediatrics stem cell transplantation, 11-bed ward;
- Adults stem cell transplantation, 25-bed ward;
- Stem cell laboratory;
- Cord blood bank;
- Cytogenetic laboratory;
- Complete evaluation, treatment and follow-up of new and previously diagnosed FA patients;
- Diagnostic testing (DEB and MMC test) and screenings of siblings;
- Genetic counseling;
- Matching sibling, unrelated, haploidentical and cord blood stem cell transplants;
- HLA registry (Iranian Stem Cell Donor Program, ISCDP).

**ISRAEL**

**International Center for Cell Therapy & Cancer Immunotherapy (CTCI)**
Weizman Center, Top Ichilov
14 Weizman Street
Tel Aviv 64239, Israel

- **Shimon Slavin, MD, Professor of Medicine, Scientific & Medical Director of CTCI**
  Telephone: 972-77-777-9255 Fax: 972-77-777-9247
  Email: slavin@CTCIcenter.com
Services Offered:
Allogeneic stem cell transplantation using well-tolerated reduced intensity conditioning towards minimizing the risk of the transplant procedure by using nonmyeloablative stem cell transplantation. Stem cell transplantation can also be considered from half-matched (haploidentically mismatched) family member while avoiding the risk of graft-versus-host disease.

Schneider Children’s Medical Center of Israel
14 Kaplan Street
PO Box 559
Petach Tikvah 49202
Israel

• Hannah Tamary, MD, Director of Pediatric Hematology, Professor of Pediatrics
  Telephone: 972-3-9253669  Fax: 972-3-9253042
  Email: htamary@post.tau.ac.il

• Joanne Yakobovich, MD, Senior Pediatric Hematologist

• Jerry Stein, MD, Director of Pediatric Bone Marrow Transplantation

Services Offered:
• Mutation detection for all Fanconi anemia genes, genetic counseling, and prenatal diagnosis;
• Comprehensive clinical care.

ITALY

G. Gaslini Children’s Institute
Largo G.Gaslini 5
16147 Genova, Italy

• Carlo Dufour, MD, Head, Hematology Unit
  Telephone: 39-010-5636-694  Fax: 39-010-5636-714
  Email: carlodufour@ospedale-gaslini.ge.it

• Johanna Svahn, MD, Hematology Unit
  Telephone: 39-010-5636-694 Fax: 39-010-5636-714
  Email: johanna.svahn@ospedale-gaslini.ge.it

• Enrico Cappelli, PhD, Hematology Laboratory
  Telephone: 39-010-5636-693 Fax: 39-010-5636-714
  Email: enricocappelli@ospedale-gaslini.ge.it

Services Offered:
• Primary diagnosis with DEB test, cell cycle analysis and MMC sensitivity, FANCD2 Ubiquitination (WB) on peripheral blood cells and fibroblasts;
• FA complementation group analysis by retroviral vectors on peripheral blood T-cells, bone marrow cells, fibroblasts and B-cell lines for groups A, C, G, D2;
• Collaboration with Dr. Helmut Hannenberg, Riley Hospital for Children, Indianapolis and Dr. Juan Bueren, CIEMAT, Madrid, Spain for remaining FA complementation group analyses;
• Collaboration with Prof. Juan Carlos Belmonte Ispizua, University LaJolla, San Diego, CA for IPS;
• Collaboration with Dr. Anna Savoia, IRCSS Burlo Garofolo, University of Trieste, Italy, for molecular diagnosis of FA;
• Collaboration with Dr Paolo Degani, Mutagenesis Lab, Scientific Tumour Institute, Genova, Italy, for redox activity;
• Haematopoiesis laboratory (cell cultures, cytokine hypersensitivity tests);
• Cytogenetic laboratory;
• Collaboration with European Centres of the EBMT (European Society for Blood and Marrow Transplantation) for data collection and retrospective studies;
• Close scientific collaboration with Dr. Grover Bagby (OHSU, Portland, OR, USA) on pathogenetic mechanism of marrow failure in FA;
• 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 (Dr. Edoardo Lanino, HSC Unit, G. Gaslini Children’s Hospital), head and neck cancer evaluation, endocrinology, orthopedic and nephrology clinic, psychological support;
• Ante-natal diagnosis available for patients in whom mutations are known;
• Experimental protocol for treatment of FA patients with bone marrow failure and no HSC donor available, using Etanercept (anti TNF-alpha); Eudract Code (Italian Ministry of Health Registration Code) 2005-003096-20. This study has now been published.

Second University of Naples
Clinica Pediatrica 1, Department of Paediatrics
Via De Grecchio 4
80138 Napoli, Italy

• Bruno Nobili, MD
  Telephone and Fax: 39-0815-665432
  Email: bruno.nobili@unina2.it

• Silverio Perrotta, MD
  Telephone and Fax: 39-0815-665421
  Email: silverio.perrotta@unina2.it

• Sofia Maria Rosaria Matarrese, MD
  Telephone and Fax: 39-0815-665444
  Email: SofiaMariaRosaria.MATARESE@unina2.it
Services Offered:

- Complete clinical evaluation, treatment and follow-up of new and previously diagnosed FA patients;
- Diagnostic testing (chromosomal breakage with Mitomycin C, DEB test, cell cycle analysis, karyotype, bone marrow examination, cytogenetic analysis, FANCD2 ubiquitination (WB) on peripheral blood cells and fibroblasts);
- Transfusion of irradiated blood and platelet products if needed;
- Information, education and assistance to families of patients with FA and referring physicians;
- Coordination of consultations with other subspecialties for management of FA-related disorders.

University of Pavia

Pediatric Haematology and Oncology Unit
Fondazione IRCCS, Policlinico San Matteo
Piazzale Golgi, 2
27100, Pavia, Italy

Prof. Franco Locatelli, MD
Telephone: 39-0382-502607 Fax: 39-0382-501251
f.locatelli@smatteo.pv.it

Services Offered:

- Hematopoietic stem cell transplantation from HLA-identical or disparate family donors and from unrelated volunteers;
- Stem cell laboratory;
- Cell therapy laboratory;
- Stem cell bank;
- Cytogenetic laboratory;
- Molecular diagnosis of Fanconi anemia.

JAPAN

Tokai University

Department of Cell Transplantation and Regenerative Medicine
Shimokasuya 143
Ishera, Kanagawa, 259-1193, Japan

Hiromasa Yabe, MD, Stem Cell Transplantation
Telephone: 81-463-93-1121 Fax: 81-463-95-9567
Email: yabeh@is.icc.u-tokai.ac.jp

Miharu Yabe, MD, Stem Cell Transplantation
Telephone: 81-463-93-1121 Fax: 81-463-95-9567
Email: miharu@is.icc.u-tokai.ac.jp

Services Offered:

- Evaluation of new and previously diagnosed patients;
- Expertise in pediatric and adult stem cell transplantation from matched sibling donor or alternative donor;
- Special interest in new conditioning regimens for patients with FA to improve long-term quality of life.
- Direct collaboration with Prof. Minoru Takata, the Kyoto University, for mutation analysis.

KENYA

Kenyatta National Hospital
Haematology & Blood Transfusion Unit
Department of Human Pathology
University of Nairobi, School of Medicine
Nairobi, Kenya

Dr. Grace W. Kitonyi MBChB, FRCPath
Haematologist/Haematopathologist
Telephone: 254 20 2721815
Mobile phone: 254722385336
Email: gwkitonyi@yahoo.com
Cc: gkitonyi@uonbi.ac.ke

Dr. Jessie N. Githanga MBChB, MMED Path
Haematologist/Haematopathologist
Telephone: 254 20 2721815
Mobile phone: 254721245721
Email: jgithanga3@gmail.com

Dr. J. A. Rajab, MBChB, MMED, Path, MPH
Haematopathologist/Public Health Specialist
Telephone: 254 20 2721815
Mobile phone: 254722707421
Email: amjamilla@yahoo.com

Services Offered:

- Diagnosis and management of all patients with FA including counseling of families;
- Coordination of consultations with other sub-specialities for management of FA related disorders.
LEBANON

St. George Hospital University Medical Center
Dept of Pediatrics and Pediatric Hematology/Oncology
Office 121
Ashrafieh, Beirut, Lebanon

- Dr. Roula Farah, MD, FAAP
  Associate Professor of Pediatrics and Pediatric Hematology/Oncology
  President, CHANCE Association
  Cell phone: 961-3-681-309
  Email: roula.fs@dm.net.lb

Services Offered:
- Complete clinical evaluation, treatment and follow-up of new and previously diagnosed FA patients;
- Prenatal diagnosis;
- Diagnostic testing (chromosomal breakage with mitomycin C, karyotype, bone marrow examination, etc.);
- Genetic testing for FANCA gene mutations;
- Transfusion of irradiated blood and platelet products if needed;
- Support with financial coverage for diagnostic studies if patient cannot afford it;
- Information, education and assistance to families of patients with FA and referring physicians;
- Genetic counseling;
- Maintenance of the National Fanconi Anemia Registry.

MEXICO

Centro Medico Nacional “La Raza”
Instituto Mexicano Del Seguro Social
Division de Trasplantes
Seris y Zaachila
Col. La Raza, 02990
Mexico DF, Mexico

- Dr. Inés Montero Ponce
- Dr. Ana Lilia Hernández Moreno

Prof. Dr. Clara Gorodezky
Head of Department of Immunology & Immunogenetics, InDRE
Secretary of Health
President of the Board of Fundacion Comparte Vida, A.C.
Francisco P. Miranda #77 - Laboratory Building, 2nd Floor, Mexico DF, 01480, Mexico
Phone: +5255 6383 0041 & +5255 5062 1600 ext. 59314 & 59397

Email: clarag@unam.mx or cgorodea@fundacioncompartevida.org.mx
www.fundacioncompartevida.org.mx

Services Offered:
- HLA Lab, ASHI accredited laboratory;
- Access to DONORMO (Mexican Unrelated Bone Marrow Donors Registry) as well as the BACECU (Mexican Unrelated Cord Blood Bank);
- HLA typing and all related studies for solid organ transplantation;
- Search DONORMO, BACECU, and BMDW, etc. and perform all the workup;
- Referrals to physicians for Fanconi anemia patients;
- We work with all the hospitals in Mexico and with many transplant centers abroad;
- We belong to BMDW and are a Coop Registry of NMDP.

Instituto Nacional de Pediatría
Instituto de Investigaciones Biomédicas
UNAM
Insurgentes Sur 3700-C
Col. Insurgentes Cuicuilco
4530 Mexico City, DJ, Mexico

Sara Frias, PhD
Telephone: 52-55-1084-5533
Email: sarafrias@biomedicas.unam.mx

Marisol González, MD
Telephone: 55-320-51010
Email: mary_solg@hotmail.com

Services Offered:
- Clinical and laboratory diagnosis of Fanconi anemia;
- Hematology in bone marrow and blood;
- Analysis of spontaneous chromosomal aberrations and chromosomal breakage test induced with DEB and MMC in lymphocytes, fibroblasts and amniocytes;
- Analysis of G2/M cell cycle halt by flow cytometry in lymphocytes and fibroblasts.

Unidad de Citogenética
Servicio de Hemato-Oncología Pediátrica, Unidad de Citogenética, Nuevo Hospital Civil
Dr. Juan I Menchaca
Laboratorio de Citogenetica Genotoxicidad y Biomonitoreo
CUCS, Universidad de Guadalajara

Juan I. Menchaca, MD
Nuevo Hospital Civic
División de Pediatría,
Servicio de Hematología Pediátrica
Unidad de Citogenética,
Salvador de Quevedo y Aubieta #750, CP-44340
Guadalajara, Jalisco, México
Telephone: 52-33-3883440 ext. 52866

Enrique Corona Rivera, MD
Universidad de Guadalajara
Centro Universitario de Ciencias de la Salud
Instituto de Genética Humana
Laboratorio de Citogenética genotoxicidad y Biomonitorio
Edificio P 2do Nivel
Sierra Mojara #950, S.L., CP-44340
Guadalajara, Jalisco, México
Telephone: 52-33-10585200 ext. 33647

Lucina Bobadilla-Morales, MD, PhD
Main contact: Diagnosis, research, and patient management
Email: lucinabo@cucs.udg.mx

Alfredo Corona-Rivera, PhD
Research and diagnostic
Email: alcoronar@gmail.com

Fernando Sánchez-Zubieta, MD
Pediatric Hemato-oncology services
Email: dfernados59@hotmail.com

Services Offered:
- Clinical and laboratory diagnosis of Fanconi anemia;
- Hematology in bone marrow and blood;
- Analysis of spontaneous chromosomal aberrations and chromosomal breakage test induced with MMC in lymphocytes;
- MLPA molecular biology studies in Fanconi anemia patient samples;
- Genetic counseling for patients, parents, and relatives;
- Diagnostic evaluation for Fanconi anemia and other bone marrow failure syndromes;
- Consultation and education for new and previously diagnosed patients and their families;
- Comprehensive clinical management of pediatric Fanconi anemia patients;
- Hematopoetic stem cell progenitors transplantation;
- Performance of HLA- A*, B*, C*, DQ*, DR*, high resolution typing;
- Cytogenetics, FISH, molecular biology, cryopreservation and flow cytometry facilities to alternative studies.

NETHERLANDS

Leiden University Medical Center
Department of Pediatrics/BMT unit
PO Box 9600
Leiden, 2300 RC, Netherlands

Arjan C Lankester, MD, PhD, Program Director Stem Cell Transplantation, Department of Pediatrics/BMT unit
Telephone: 31-71-5264131 Fax: 31-71-5248198
Email: A.Lankester@lumc.nl

UMC Utrecht
Kinderarts - Hematoloog
Wilhelmina Kinderziekenhuis
Postbus 85090
3508 AB Utrecht
Huispostnr KC 03.063.0, Netherlands

Marc Bierings, MD, PhD, Represents the Dutch Fanconi Anemia Guideline on behalf of the Dutch Childhood Oncology Group (DCOG), and Chairs the Guideline Committee for FA in Netherlands.
Telephone: 31 (0)88 7554344 Fax: 31 (0)88 7555350
Email: m.bierings@umcutrecht.nl

VU University Medical Center Amsterdam
Department of Clinical Genetics
Van der Boechorststraat 7
NL-1081 BT Amsterdam, Netherlands

Diagnosis:
Telephone: 31-20-444-8346 Fax: 31-20-444-8293

Hans Gille, PhD
Email: jgp.gille@vumc.nl

Resie Vervenne, PhD
Email: r.vervenne@vumc.nl

Pino Poddighe, PhD
Contact for chromosomal breakage testing.
Email: p.poddighe@vumc.nl

Research:
Telephone: 31-20-444-8270 Fax: 31-20-444-8285

Josephine C. Dorsman, PhD
Email: jc.dorsman@vumc.nl

Services Offered:
Diagnosis:
- Diagnosis by chromosomal breakage analysis, including mosaicism;
- Molecular diagnosis by mutation screening of all known FA genes;
- Prenatal DNA testing (if mutations are known).

Research:
- Identification of the genes responsible for FA and “overlapping” conditions;
- Understanding the FA pathway and how a defect in the pathway causes FA-specific clinical symptoms;
- Discovery of FA pathway defects and their role in sporadic cancer.

**Collaboration in Netherlands:**
- **M. Bierings, MD, PhD.** Stem Cell Transplantation, Clinical Coordinator for FA families in The Netherlands, Utrecht University Medical Center
- **E.T. Korthoff, MD, PhD.** Stem Cell Transplantation, Leiden University Medical Center
- **R.H. Brakenhoff, PhD.** Dept. Otolaryngology/Head-Neck Surgery, VU University Medical Center Amsterdam.

**NEW ZEALAND**

**Christchurch Hospital**

**Children’s Haematology Oncology Centre**

Private Bag 4710
Christchurch 8140, New Zealand

- **Dr. Siobhan Cross**, Paediatric Haematologist
  Telephone: 64 3 364 0640, ext. 87500
  Email: Siobhan.Cross@cdhb.govt.nz

**Services Offered:**
- FA diagnosis (samples are sent to Australia), follow up/surveillance for FA patients under age 18.

**Starship Children’s Hospital**

Grafton
Auckland 1023, New Zealand

- **Dr. Nyreee Cole**
  Telephone: 64 9 307 4919
  Email: Nyreeec@adhb.govt.nz

**SAUDI ARABIA**

**King Faisal Specialist Hospital & Research Center**

Riyadh, Saudi Arabia

- **M. Ayas, MD, Head, Section of Pediatric Stem Cell Transplantation Department of Pediatric Hematology Oncology**
  Telephone: 966-1-442-3934 Fax: 966-1-442-4662
  Email: mouhab@kfshrc.edu.sa

**Services Offered:**
- Diagnosis: cytogenetics testing including DEB chromosomal breakage testing and conventional cytogenetics of bone marrow and peripheral blood;
- Comprehensive care for FA patients, including blood and platelet transfusion;
- Allogeneic stem cell transplant: matched related bone marrow and matched/partially matched unrelated cord blood transplants;
- Haploidentical stem cell transplantation for FA patients with no matched related donors.

**REPUBLIC OF KOREA**

**Seoul St. Mary's Hospital**

**The Catholic University of Korea**

Blood & Marrow Transplantation Center
#222 Banpo-daero, Seocho-gu
Seoul, 137-701, Republic of Korea
Telephone: 82-10-9407-2220 Fax: 82-2-537-4544

- **Nack-Gyun Chung, MD, Professor, Department of Pediatrics, Hematology/Oncology/BMT**
  Telephone: 82-2-2258-6188 Fax: 82-2-537-4544
  Email: cngped@catholic.ac.kr

- **Myungshin Kim, MD, PhD.** Professor, Department of Laboratory Medicine
  Telephone: 82-2-2258-1645 Fax: 82-2-2258-1719
  Email: microkim@catholic.ac.kr

**Services Offered:**
- Evaluation of new and previously diagnosed patients;
- Breakage test, sequence analysis;
- Diagnosis and management of all patients with FA including counseling of families;
- Expertise in stem cell transplantation from matched sibling donor or alternative donor.

**SINGAPORE**

**National University Hospital, Singapore**

Department of Paediatrics
1E Kent Ridge Road
NUHS Tower Block Level 12
Singapore 119228
Republic of Singapore
http://www.nuh.com.sg/ucmi/

- **Poh-Lin Tan, MBBS, MMED** (Paediatrics)
  Email: poh_lin_tan@nuhs.edu.sg
International Patient Liaison Centre:
Telephone (24hr Helpline): (65) 67792777
Email: iplc@nhg.com.sg

Services Offered:
- FACT-accredited paediatric blood and marrow transplant;
- Paediatric sub-specialties: adolescent medicine, allergy, cardiology, developmental paediatrics, endocrinology, gastroenterology, genetics, haematology, infectious diseases, intensive care, nephrology, neurology, oncology, otorlaryngology, psychiatry, pulmonology, rheumatology, surgery.

SOUTH AFRICA

**Chris-Hani Baragwanath Hospital**
Division of Haematology and Oncology
Johannesburg, South Africa

- Dr. Linda Wainwright
  Clinic Telephone: 0800333555
  Office Telephone: 0119339594
  Cell: 0828219985
  Email: rosalind.wainwright@wits.ac.za

**Johannesburg Hospital**
Division of Haematology and Oncology
Dep. of Pediatrics
Private Bag X39
Johannesburg 2000, South Africa

- Prof. Janet Poole
  Telephone: 27(0)114883294/0 Fax: 27(0)114884152
  Cell: 27(0)824695762
  Email: Janet.Poole@wits.ac.za

**NHLS, Division of Human Genetics**
University of the Witwatersrand
PO Box 1038
Johannesburg 2000, South Africa

- Dr. Amanda Krause
  Telephone: 27-11-489-9219/9224
  Mobile:27-82-809-5797
  Fax: 27-11-489-9226
  Email: amanda.krause@nhls.ac.za

Services Offered (Chris-Hani Baragwanath, Johannesburg Hospital, and NHLS):
- Genetic counseling service for families with FA;
- Diagnostic, carrier, preclinical and prenatal testing.

**Units Hospital**
PO Box 15225
Lyttleton, 0140, Pretoria
Gauteng, South Africa

- Dr. Charmaine Jacobs, MD, Pediatric Oncology/Haematology Unit
  Telephone: 27-12-6778076
  Mobile Phone: 27724195346 Fax: 27-12-6647848
  Email: cjaconko@mweb.co.za

Services Offered:
- Diagnosis and management of FA patients and their families of all age groups;
- Coaching and counseling families towards a healthy and optimum lifestyle with FA;
- Coordination of consultations with other sub-specialties for management of FA-related disorders;
- Motivational speaking presentation on living a life with Fanconi with meaning and purpose;
- Workshops on: Lifestyle management for Fanconi families - empowering the patients to live their best life.

**University of the Free State**
PO Box 339(G69)
Bloemfontein 9300, South Africa

- Prof. D.K. Stones, Paediatric Oncology and Haematology, Department of Paediatrics and Child Health
  Telephone: 27-51-4052820
  Mobile: 083-444-7233
  Fax: 27-51-4443230
  Email: StonesDK@UFS.ac.za

Services Offered (Universitas Hospital, Bloemfontein and NHLS):
- Genetic counseling service for families with FA;
- Diagnostic, carrier, preclinical and prenatal testing in conjunction with genetics department and NHLS.

**SPAIN**

**Hospital General Universitario Gregorio Marañón**
Pediatric Hematology
C/Doctor Esquerdo, 46
28007 Madrid, Spain

- Dr. Cristina Belendez
  Telephone: 91-529-00-37
  Email: cristina.belendez@salud.madrid.org
Hospital Universitario de la Princesa
C/Doctor Esquerdo, 45
28028 Madrid, Spain

- Dr. Ángela Figuera
  Telephone: 91-520-24-31
  Email: afiguera.hlpr@salud.madrid.org

Hospital Vall d’Hebron
Pediatric Oncology
P. de la Vall d’Hebron 119-129
Barcelona 08035, Spain

- Dr. Cristina Díaz de Heredia
  Telephone: 93-488-30-93

University Hospital Niño Jesús
Avenida Menéndez Pelayo, 65
28009 Madrid, Spain

- Julian Sevilla, MD, Department of Hematology and Oncology
  Telephone: 91-503-5938 Fax: 91-503-5960
  Email: jsevilla.hnjs@salud.madrid.org

- Dr. Marta Prudencio, Department of Hematology and Oncology
  Telephone: 91-503-5938 Fax: 91-503-5960

CIEMAT/CIBERER
Division of Hematopoietic Innovative Therapies (HIT)
CIEMAT/ CIBER of Rare Diseases (CIBERER)
IIS Jiménez Díaz Foundation
Madrid, Spain
www.ciemat.es
Spanish Fanconi Anemia Network: www.redfanconi.org

- Juan Bueren, PhD, Head of Division of Hematopoietic Innovative Therapies (HIT)/CIBER of Rare Diseases (CIBERER)/IIS Jiménez Díaz Foundation
  Telephone: 34-91-346-6518
  Email: juan.bueren@ciemat.es

- José A. Casado, Senior Researcher of Division of Hematopoietic Innovative Therapies (HIT)/CIBER of Rare Diseases (CIBERER)/IIS Jiménez Díaz Foundation
  Telephone: 34-91-496-2525
  Email: jose.casado@ciemat.es

- Paula Río, Researcher of Division of Hematopoietic Innovative Therapies (HIT)/CIBER of Rare Diseases (CIBERER)/IIS Jiménez Díaz Foundation
  Telephone: 34-91-346-0890
  Email: paula.rio@ciemat.es

- Susana Navarro, Senior Researcher/CIBER of Rare Diseases (CIBERER)/IIS Jiménez Diaz Foundation
  Telephone: 34-91-346-0891
  Email: s.navarro@ciemat.es

- Mª Luz Lozano, Technical Assistance/CIBER of Rare Diseases (CIBERER)/IIS Jiménez Diaz Foundation
  Telephone: 34-91-346-6255
  Email: luz.lozano@ciemat.es

- Aurora de la Cal, Secretary, Spanish FA Research Network
  Telephone: 34-91-496-2518
  Email: aurora.delacal@ciemat.es

Services Offered:
- Coordination of the FA Spanish registry;
- Coordination of the FA gene therapy clinical trial;
- FA subtyping by retrovirus mediated gene transfer;
- Analysis of the hematopoietic reserve in bone marrow samples from FA.

Universitat Autònoma de Barcelona
Chromosome Fragility Service (UAB-CFS)
Department of Genetics and Microbiology
08193 Bellaterra (Cerdanyola del Valles)
Barcelona, Spain
http://safcro.uab.es/
Spanish Fanconi Anemia Network: www.redfanconi.org

- Jordi Surrallés, PhD, Professor of Genetics (UAB-CFS Scientific Director)
  Telephone: 34-935-811-830 Fax: 34-935-812-387
  Email: jordi.surralles@uab.es

- Maria Roser Pujol, PhD, Cytogeneticist (UAB-CFS Technical Director). Accredited by Spanish Society of Human Genetics
  Fax: 34-935-812-387
  Email: MariaRoser.Pujol@uab.cat

Services Offered:
- DEB chromosomal breakage testing in blood and skin fibroblasts;
- Diagnosis of mosaicism;
- MMC-induced G2/M-cell phase arrest assay;
- FANCD2 monoubiquitination and foci formation assays;
- Spanish contact for prenatal diagnosis;
- Genetic counseling;
- Maintenance of a biobank of Spanish FA patients with cryopreserved transformed cell lines and DNA.

Services for genetic analysis are offered free of charge to Spanish FA patients through the Spanish Fanconi Anemia Network, which is funded by the Spanish Ministry of Health. Chromosome fragility testing in blood lymphocytes or skin
fibroblast is free of charge to Spanish patients when the results are positive. The cost of the DEB test in blood lymphocytes to non-Spanish patients or to Spanish patients with a negative result is 290 euros. The cost of the DEB test in fibroblasts to non-Spanish patients and to Spanish patients with a negative result is 450 euros.

TURKEY

Hacettepe University
Inherited Bone Marrow Failure Center
Ankara, Turkey 06100

- Sule Unal, MD. Director, Associate Professor
  Telephone: +90 312 305 1170
  Email: suleunal@hacettepe.edu.tr

Services Offered:
- NGS screening is available for genetic diagnosis of FA.
- FA patients are followed by experienced physicians in their fields. Each patient is seen by the same hematologist, ENT, O&G, plastic surgeon on visits. Both adult and pediatric patients are followed and the facility is approved by the Turkish Ministry of Health.
- Hematopoietic stem cell transplantation unit has good results with FA patients.

Istanbul University
Bone Marrow Bank & Department of Medical Biology
Istanbul Medical Faculty
Çapa 34390 Istanbul, Turkey

- Nevin Yalman, MD, President, Fanconi Anemia Association, Professor, Pediatric Hematologist
  Telephone: 9-212-414-20-00, x 31208
  Fax: 9-212-635-11-68
  Email: nevinyalman@gmail.com

UNITED KINGDOM

Birmingham Children’s Hospital
Steashouse Lane
Birmingham, West Midlands B4 6NH, United Kingdom

- Phil Darbyshire, MD, Consultant Pediatric Hematologist
  Telephone: 44-121-333-9999
  Email: Phil.Darbyshire@bch.nhs.uk

Bone Marrow Transplant & Late Effects Clinic
Department of Haematology
Royal Hallamshire Hospital
Glossop Road
Sheffield S10 2JF, United Kingdom

- Professor John Snowden, BSc (Hons), MBChB, MD, FRCP, FRCPath
  Consultant Haematologist
  Telephone: 0114-271-3357 Fax: 0114-271-3997
  Email: John.Snowden@sth.nhs.uk

- Dr Diana Greenfield, BSc (Hons), RN, PhD
  Consultant Nurse
  Telephone: 0114-226-5592 Fax: c/o 0114-271-3754
  Email: Diana.Greenfield@sth.nhs.uk

Services Offered:
- The joint Bone Marrow Transplant and Late Effects Clinic provides adult Fanconi anaemia patients access to a multi-disciplinary team providing initial general assessment, confirmation of diagnosis and subsequent coordination of screening and support. The multi-disciplinary clinic provides access to other specialists at our hospital including: endocrinology, respiratory, gynaecology, urology, gastroenterology, maxillo-facial, radiology, genetics, nutrition, psychiatry, psychology and lifestyle advice. There is close transitional working with the paediatric services run by Prof. Ajay Vora at Sheffield Children’s Hospital NHS Foundation Trust.
- Patients are assessed and reviewed in Sheffield with communication to their referring clinician. Nurse-led follow-up and support is recommended on an annual basis for all those patients who are medically stable.
- Where appropriate, haematopoietic stem cell transplantation can be arranged in Sheffield. Both the Sheffield Teaching Hospitals NHS Foundation Trust and Sheffield Childrens’ Hospital are JACIE-accredited centres.

Bristol Royal Hospital for Children
Oncology Day Beds
Level 6
Upper Maudlin Street
Bristol, BS2 8BJ, United Kingdom

- Colin Steward, MA, BM, BCh, PhD, FRCPCH, FRCP, Department of Paediatric Haematology and Bone Marrow Transplantation
  Telephone: 44-117-3420844 Fax: 44-117-3420170
  Email: colin.steward@uhbristol.nhs.uk

Services Offered:
- Comprehensive diagnostic and routine haematological care in specialized clinic;
- Coordination of complementation group analysis, mutation analysis and somatic mosaicism studies;
- Expertise in androgen and transplantation therapy;
- Specialists in genetics, haematology, bone marrow transplantation (from sibling, matched and mismatched unrelated, haploidentical and cord donors), endocrinology, gastroenterology and radiotherapy;
- 16-bed inpatient area and outpatient bone marrow transplantation clinic.

**St. Mary’s Hospital**  
Praed Street, Paddington  
London W2 1NY, United Kingdom

- **Josu de la Fuente, PhD FRCP MRCPCH FRCPath**  
  Consultant Pediatric Hematologist  
  Telephone: 44-20-788-66164  
  Email: Josu.delaFuente@imperial.nhs.uk

**Yorkshire Paediatric Haematology Unit**  
Leeds General Infirmary  
Fanconi Anaemia – Multi-disciplinary Clinic  
Great George Street  
Leeds LS1 3EX, United Kingdom

- **Professor Sally E. Kinsey, MD**, Pediatric Haematologist

---

**Services Offered:**
The Fanconi Anaemia multi-disciplinary clinic provides initial general assessment of cases and confirmation of diagnosis. The multi-disciplinary clinic provides direct access to various specialists.

Patients are assessed and reviewed in Leeds with communication to their referring clinician. Follow-up in the multi-disciplinary clinic is recommended on a yearly basis. Geographically local individuals can have routine follow-up (including blood counts, biochemistry, ultrasound examinations, bone marrow review etc) in Leeds. Individuals living more distant can have care coordinated via their referring clinician.

Where appropriate, work-up for stem cell transplantation can be arranged in Leeds.
International
Fanconi Anemia
Testing Resources
# International Fanconi Anemia Testing Resources

<table>
<thead>
<tr>
<th>Country</th>
<th>Institution</th>
<th>Test</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Australia</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Children’s Hospital at Westmead</strong></td>
<td>DEB/MMC diagnostic testing for patients and family (Accredited by the National Association of Testing Authorities, Australia).</td>
</tr>
<tr>
<td></td>
<td>Sydney, Australia</td>
<td>Next generation sequencing on trial basis.</td>
</tr>
<tr>
<td></td>
<td><strong>Zhan he Wu, MD, PhD, FFSc (RCPA)</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>0061-2-98453236</td>
<td></td>
</tr>
<tr>
<td></td>
<td><a href="mailto:zhan.wu@health.nsw.gov.au">zhan.wu@health.nsw.gov.au</a></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Canada</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Hospital for Sick Children</strong></td>
<td>DEB/MMC diagnostic testing (Licensed under the Ontario Ministry of Health and Long Term Care).</td>
</tr>
<tr>
<td></td>
<td>Toronto, Canada</td>
<td>Canadian Inherited Marrow Failure Registry (Enrollment of patients on this research study includes data collection and sample repository).</td>
</tr>
<tr>
<td></td>
<td><strong>Yigal Dror, MD</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(416) 813-5630</td>
<td></td>
</tr>
<tr>
<td></td>
<td><a href="mailto:yigal.dror@sickkids.ca">yigal.dror@sickkids.ca</a></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Germany</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Heinrich Heine University Medical Center</strong></td>
<td>Complementation Group (Research).</td>
</tr>
<tr>
<td></td>
<td>ENT (HNO) Lab</td>
<td>Use of retroviruses for A, B, C, D2, E, F, G, I, J, L, M, N, O, P in primary T-cells, bone marrow or fibroblast cells or in lymphoblast cell lines (LCL).</td>
</tr>
<tr>
<td></td>
<td>Düsseldorf, Germany</td>
<td>FANCD2 western blot.</td>
</tr>
<tr>
<td></td>
<td><strong>Helmut Hanenberg, MD</strong></td>
<td>Coordinator of the Fanconi Anemia Registry (FAR01) in Germany, Austria, and Switzerland, together with Christian Kratz, MD, Hannover Medical School, Germany.</td>
</tr>
<tr>
<td></td>
<td>49-211-811-0832 or 0830</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Fax: 0839</td>
<td></td>
</tr>
<tr>
<td></td>
<td><a href="mailto:Hanenberg@uni-duesseldorf.de">Hanenberg@uni-duesseldorf.de</a></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Germany</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>University of Würzburg</strong></td>
<td>MMC Diagnostic Testing (Certified under Governmental and Societies).</td>
</tr>
<tr>
<td></td>
<td>Würzburg, Germany</td>
<td>FANCD2 western blot.</td>
</tr>
<tr>
<td></td>
<td><strong>Detlev Schindler, MD, PhD</strong></td>
<td>Prenatal Diagnosis.</td>
</tr>
<tr>
<td></td>
<td>+49-931-888 ext. 4088, 4098, or 4075</td>
<td>Mutation Analysis (Certified under Governmental and Societies).</td>
</tr>
<tr>
<td></td>
<td><a href="mailto:schindler@biozentrum.uni-wuerzburg.de">schindler@biozentrum.uni-wuerzburg.de</a></td>
<td>Complementation Group.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Carrier testing.</td>
</tr>
<tr>
<td>Country</td>
<td>Institution</td>
<td>Test</td>
</tr>
<tr>
<td>-----------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Netherlands</strong></td>
<td>VU University Medical Center Amsterdam, Netherlands</td>
<td>Mutation analysis <strong>FANCA</strong> (<em>Clinically Certified</em>).</td>
</tr>
<tr>
<td></td>
<td>Hans Gille, PhD 31-20-444-8346 <em><a href="mailto:jjp.gille@vumc.nl">jjp.gille@vumc.nl</a></em></td>
<td>Mutation analysis <strong>FANCC</strong>, <strong>-E, -F, and -G</strong> (<em>Clinically Certified</em>).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mutation analysis of other <strong>FANC</strong> genes (<em>Clinically Certified</em>).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Prenatal DNA diagnosis (<em>Clinically Certified</em>).</td>
</tr>
<tr>
<td><strong>Republic of Serbia</strong></td>
<td>Laboratory for Medical Genetics</td>
<td>DEB diagnostic testing performed in patients with symptoms of FA and on request of the physician/hematologist. Test siblings of DEB-positive patients, but only if requested.</td>
</tr>
<tr>
<td></td>
<td>Mother and Child Health Care Institute of Serbia</td>
<td></td>
</tr>
<tr>
<td></td>
<td>St. Radoja Dakica 6-8 11070 Belgrade, Republic of Serbia</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Marina Djurisic, PhD 381-11-3108273 <em><a href="mailto:genetika@imd.org.rs">genetika@imd.org.rs</a></em></td>
<td></td>
</tr>
<tr>
<td><strong>Spain</strong></td>
<td>Hematopoiesis and Gene Therapy Division, CIEMAT/CIBER of Rare Diseases (CIBERER) Madrid, Spain <em><a href="http://www.ciemat.es">www.ciemat.es</a></em></td>
<td>Coordination of the Spanish FA Registry.</td>
</tr>
<tr>
<td></td>
<td>Juan Bueren, PhD, Head of Hematopoiesis and Gene Therapy 34-91-346-6518 <em><a href="mailto:juan.bueren@ciemat.es">juan.bueren@ciemat.es</a></em></td>
<td>Studies of G2/M cell cycle arrest in fibroblasts in FA patients with mosaicism in peripheral blood and subtyping by reversion of G2/M arrest with retroviral vectors (<strong>A,C,G</strong>) (Research).</td>
</tr>
<tr>
<td></td>
<td>José A. Casado, Senior Researcher 34-91-496-2525 <em><a href="mailto:jose.casado@ciemat.es">jose.casado@ciemat.es</a></em></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Aurora de la Cal, Secretary of the Spanish FA Research Network 34-91-496-2518 <em><a href="mailto:aurora.delacal@ciemat.es">aurora.delacal@ciemat.es</a></em></td>
<td></td>
</tr>
<tr>
<td>Country</td>
<td>Institution</td>
<td>Test</td>
</tr>
<tr>
<td>---------</td>
<td>-------------</td>
<td>------</td>
</tr>
<tr>
<td>Spain</td>
<td>Universitat Autònoma de Barcelona/CIBER of Rare Diseases (CIBERER) Barcelona, Spain Spanish Fanconi Anemia Network: <a href="http://www.redfanconi.org">www.redfanconi.org</a> <a href="http://safcro.uab.cat">http://safcro.uab.cat</a> Jordi Surrallés, PhD 34-935-811-830 <a href="mailto:jordi.surralles@uab.cat">jordi.surralles@uab.cat</a> Maria Roser Pujol, PhD Cytogeneticist (UAB-CFS Technical Director) <a href="mailto:MariaRoser.Pujol@uab.cat">MariaRoser.Pujol@uab.cat</a></td>
<td>Coordination of the Spanish FA Biorepository (biobank of DNA and cell lines from FA patients). DEB diagnostic testing, diagnosis of mosaicism (certified by Societies). Studies of G2/M cell cycle arrest in fibrobasts, FANCD2 ubiquitination and foci formation, western blot of FA proteins. (Research) Mutation analysis (Research) for Spanish gypsy population. Carrier testing is available for family members when mutations are known in the affected case (sibling, etc.) Genetic characterization (subtyping and mutation analysis) of FA patients is done in the lab for Spanish families under the financial umbrells of research grants. Service is not free of charge to non-Spanish patients.</td>
</tr>
</tbody>
</table>

**Please note:**
- The laboratories listed are CLIA (Clinical Laboratories Improvement Amendments)-certified.
- Estimated costs for diagnostic tests range from approximately $1,000 - $1,200. Check with your insurance company for coverage. The average turnaround time for testing results is about 10 working days. For more information, please contact the labs directly.
- Additional testing information for Fanconi anemia is available at: [http://geneclinics.org](http://geneclinics.org)
  Select “Gene Reviews”
  Select “Search by Disease”
  Enter “Fanconi anemia” into the text box
- “Research” indicates that results may only be used for research purposes, meaning results may not be shared with referring physical/family.
Index of Institutions and Clinicians

A
Adair, Jennifer ................................................................................. 5
Adler-Brecher, Barbara ................................................................. 6
Agarwal, Rajni ................................................................................ 8
Alter, Blanche P. ............................................................................. 7
Andrews, Laura .............................................................................. 1
Apollo Specialty Hospital ............................................................... 28
Armenian, Saro .............................................................................. 3
Auerbach, Arleen D. ...................................................................... 6
Ayas, M. .......................................................................................... 33
B
Baker, K. Scott ................................................................................. 5
Balasa, Vinod ................................................................................... 1
Barbach, Nancy .............................................................................. 4
Bass Center for Childhood Cancer and Blood Diseases ... 8
Be The Match ................................................................................... 11
Becker, Pam .................................................................................... 5
Belendez, Cristina .......................................................................... 34
Bertuch, Alison ............................................................................... 9
Bhatia, Smita ................................................................................... 3
Bierings, Marc ............................................................................... 32, 33
Birmingham Children’s Hospital .................................................... 36
Bobadilla-Morales, Lucina ............................................................. 32
Bone Marrow Transplant & Late Effects Clinic .............................. 36
Bonfim, Carmen ............................................................................ 24
Borkhardt, Arndt ............................................................................ 27
Boston Children’s Hospital ............................................................. 4
Boston Foundation for Sight ........................................................... 15
Bouidar, Farid .................................................................................. 6
Bower, Matt .................................................................................... 22
Brazenoff, R.H. ............................................................................. 33
Breech, Lesley ................................................................................ 2
Brennan, Lisa L. ............................................................................. 4
Brigham and Women’s Hospital .................................................... 12
Bristol Royal Hospital for Children ............................................... 36
Buener, Juan .................................................................................... 35, 41
C
Cabanillas, Christina .................................................................... 3
Califano, Joseph .............................................................................. 3
California, University of, at San Francisco .................................... 16
Camero, Elizabeth ......................................................................... 18
Capital Institute of Pediatrics ....................................................... 25
Cappelli, Enrico ............................................................................... 29
Carter, Tina ................................................................................... 23
Casado, José A. ............................................................................. 35, 41
Casper, Keith A. ............................................................................ 17
Castiel, Mercedes .......................................................................... 7, 14
Centro Médico Imbanaco de Cali ................................................... 26
Centro Medico Nacional ................................................................. 31
Charité, Campus Virchow Klinikum, University Medicine, Berlin .................................................................................. 27
Chhabra, A. Bobby .......................................................................... 15
Chicago, University of ................................................................... 16
Chicka, Michael ............................................................................. 21
Children’s Health Dallas .................................................................. 10
Children’s Hospital at Westmead .................................................... 23, 40
Children’s Hospital Central California ........................................... 1
Children’s Hospital Los Angeles, University of Southern California ................................................................. 1
Children’s Hospital of Wisconsin ..................................................... 1
Chris-Hani Baragwanath Hospital ................................................... 34
Christchurch Hospital, Children's Haematology Oncology Centre ............................................................................. 33
Chung, Nack-Gyun ........................................................................ 33
CIEMAT/CIBERER ....................................................................... 35, 41
Cincinnati Children’s Hospital Medical Center ............................... 2, 12, 13, 14, 16, 20
Cincinnati, University of ................................................................ 17
City Of Hope ................................................................................... 3
Clausen, Niels ................................................................................ 26
Clinica Las Americas ...................................................................... 25
Cogan, Mary ................................................................................... 4
Cohen Children’s Medical Center of New York, Bone Marrow Failure Program ................................................................. 3
Cohen, Laurie .................................................................................. 4
Cohn, Richard ................................................................................ 24
Cole, Catherine ............................................................................ 23
Cole, Nyree .................................................................................... 33
Coll, Yadira .................................................................................... 25
Collins, Joyce ................................................................................ 3
Cord Blood Registry ....................................................................... 11
Cornell University, Weill Medical College ..................................... 16
Cornwall, Roger ............................................................................. 2, 14
Corana-Rivera, Alfredo .................................................................. 32
Cowell, Chris ................................................................................ 23
Cowen, Edward ............................................................................ 8, 12
Cross, Siobhan ............................................................................... 33
Curtin, Julie .................................................................................... 23
D
D’Andrea, Alan ................................................................................ 4, 20
Dalle, Jean-Hugues ........................................................................ 26
Daluiski, Aaron ............................................................................... 15
Dana-Farber Cancer Institute ......................................................... 4, 20
Darbyshire, Phil ............................................................................. 36
Davies, Stella ................................................................................ 2, 6
de la Cal, Aurora .......................................................................... 35, 41
de la Fuente, Josu ........................................................................... 37
Delete Blood Cancer DKMS ............................................................ 11
Dermatology Consultation Service at the NIH Clinical Center .................................................................................. 8, 12
Díaz de Heredia, Cristina ............................................................... 35
DiVasta, Amy .................................................................................. 4
Djurisic, Marina ............................................................................. 41
Doernbecher Children’s Hospital .................................................... 41
Dorsman, Josephine ....................................................................... 32
Doyle, John J. ............................................................................... 25
Dror, Yigal .......................................................... 25, 40
Dufour, Carlo .................................................. 29

E
Eunice Kennedy Shriver National Institute of Child Health and Human Development ........................................ 8, 14
Ewing, Nadia .......................................................... 3

F
Fanconi Anemia and Bone Marrow Failure
Multidisciplinary Clinic at the Dana-Farber/Boston Children’s Cancer and Blood Disorders Center ....... 4
Fanconi Anemia Comprehensive Care Center 2, 12, 13, 14, 16
Fanconi Anemia Comprehensive Care Center Bone Marrow Failure Clinic ...................................................... 20
Fanconi Anemia Comprehensive Care Program .................................................................................................. 9
Fanconi Anemia Comprehensive Care Program .................................................................................................. 12
Fanconi Anemia Comprehensive Care Program .................................................................................................. 14
Fanconi Anemia Comprehensive Care Program .................................................................................................. 17
Farah, Roula .......................................................... 31
Ferguson, Michael .................................................. 4
Fidler, Pat .................................................................. 9
Figuera, Ángela .......................................................... 35
Filipone, Linda .......................................................... 15
Folmer, Kelly ............................................................ 1
Fontana, Gillian ...................................................... 15
Fred Hutchinson Cancer Research Center .................................................. 5
Frias, Sara .................................................................. 31
Fulcher, Maureen ...................................................... 15

G
G. Gaslini Children’s Institute .................................................. 29
Gassas, Adam .................................................................. 25
Genesis Genetics ........................................................ 18
Ghavamzadeh, Ardeshir .................................................. 28
Ghebre, Rahel G. .......................................................... 9, 14
Giannetta, Tere ............................................................ 1
Gille, Hans .................................................................. 32, 41
Gillette Children’s Specialty Healthcare ................................... 14
Gillo, Alfred P. ............................................................ 6
Giri, Neelam ............................................................... 7
Githanga, Jessie N. ........................................................ 30
Glader, Bertil .............................................................. 8
Goebel, Jens ................................................................. 2
González, Marisol ........................................................ 31
Goodridge, Erica L. ...................................................... 2, 20
Gorodezky, Clara ........................................................ 31
Grandis, Jennifer Rubin ............................................ 16
Greenberger, Joel ........................................................ 18
Greenfield, Diana ........................................................ 36
Guinan, Eva C. ............................................................ 4
Gutierrez, Lisa ............................................................ 3
Gynecology Consultation Service at the NIH Clinical Center ............................................................................... 8

H
Hacettepe University .................................................. 36
Hackensack University Medical Center ..................................... 6
University of Tuebingen ............................................................... 27
University of Virginia Health System ...................................... 15
University of Würzburg ............................................................... 40

V
Van Heest, Ann E. ................................................................. 9, 14
Van Waes, Carter ................................................................. 8, 16
Vance, Gail H. ........................................................................ 20
Velleuer, Eunike ................................................................. 27
Vervenne, Resie ....................................................................... 32
Virginia, University of, Health System .................................... 15
Vlachos, Adrianna ............................................................... 3
Vokes, Everett ........................................................................ 16
VU University Medical Center ............................................... 32, 41

W
Wagner, John E. ...................................................................... 9
Wainwright, Linda ................................................................. 34
Walsh, Christopher ............................................................... 7
Weill Cornell Medical Associates .......................................... 14
Weill Medical College .......................................................... 16
Weinberg, Kenneth ................................................................ 8
Wells Center ............................................................................ 20
Williams, David A. ............................................................... 4
Wilson, Keith M. .................................................................... 17
Wilson, Meredith ................................................................. 23
Witwatersrand, University of the ........................................ 34
Wolfson, Julie .......................................................................... 3
Wood, Robert E. ..................................................................... 3
Wooffrey, Ann ....................................................................... 5
Wu, Bai-Lin ............................................................................. 4
Wu, Zhan he ........................................................................ 40
Würzburg, University of ....................................................... 40

Y
Yabe, Hiromasa ....................................................................... 30
Yabe, Miharu ......................................................................... 30
Yakobovich, Joanne ............................................................. 29
Yalman, Nevin ....................................................................... 36
Yorkshire Paediatric Haematology Unit .................................. 37
Young, Jo-Anne H. .............................................................. 9
Young, Pamela ................................................................. 1

Z
Zhao, Mingfeng ....................................................................... 25
Zimmer, Lee A. ..................................................................... 17