



Fanconi Anemia  
RESEARCH FUND, INC.

International Treatment and Testing  
Resource Guide

**2012**



## OUR MISSION

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



# Fanconi Anemia

RESEARCH FUND, INC.

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# US Fanconi Anemia Treatment Resource Guide

Editors' Note and Disclaimer: The resource list provided in this guide is not comprehensive. Inclusion on the list does not imply endorsement by the Fanconi Anemia Research Fund, Inc.

## BONE MARROW FAILURE

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

#### Children's Hospital Boston

300 Longwood Ave.  
Boston, MA 02115

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

- **David A. Williams, MD**  
Telephone: 617-919-2697  
E-mail: [dawilliams@childrens.harvard.edu](mailto:dawilliams@childrens.harvard.edu)
- **Colin Sieff, MB BCh**  
Telephone: 617-355-2984  
E-mail: [colin.sieff@childrens.harvard.edu](mailto:colin.sieff@childrens.harvard.edu)
- **Tara Barlow, PA**  
**Program Coordinator**  
Telephone: 617-355-8246 Fax: 617-730-0641  
E-mail: [fa-bmf@childrens.harvard.edu](mailto:fa-bmf@childrens.harvard.edu)

#### Dana-Farber Cancer Institute

450 Brookline Avenue  
Boston, MA 02215

<http://research.dfci.harvard.edu/dandrealab>

- **Alan D'Andrea, MD**  
Telephone: 617-632-2080  
E-mail: [alan\\_dandrea@dfci.harvard.edu](mailto:alan_dandrea@dfci.harvard.edu)
- **Lisa A. Moreau, MS, CLSpCG**  
Telephone: 617-632-6302  
E-mail: [lisa\\_moreau@dfci.harvard.edu](mailto:lisa_moreau@dfci.harvard.edu)

#### Specialists:

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

(Continued on the next page)

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

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

#### **Services Offered:**

- ◆ Our Program Coordinator arranges a comprehensive evaluation for each new patient, including confirmation of diagnosis, genetic typing, HLA typing, and a multi-system evaluation. The team carefully examines previous diagnostic test results and past medical history to guide the initial evaluation in the multi-disciplinary clinic. This results in a written summary and recommendations for the referring physician and the patient's family. Ongoing care may continue at Children's or in partnership with the referring physician. Psychosocial support is available and an important part of our long-term care of families of patients with serious diseases.
- ◆ A variety of innovative clinical trials are available for enrollment. Two current studies for patients with Fanconi anemia are: 1) the use of danazol, an androgen and 2) a hematopoietic stem cell transplantation trial for those lacking a genotypically identical donor.
- ◆ Diagnosis of new FA patients through Clinical Laboratory Improvement Act (CLIA) certified diepoxybutane (DEB) test.
- ◆ Facilitation of DNA mutation identification via CAP/CLIA certified DNA sequencing in the Laboratory Medicine Department at Children's Hospital Boston coordinated with Dr. Bai-Lin Wu and Ann Reinhard. Current available testing for FANCA, FANCC, and FANCG are listed at [www.genetests.org](http://www.genetests.org). Genetic Counselor: Ann E. Reinhard, MS, CGC, phone: 617-355-4907, [ann.reinhard@childrens.harvard.edu](mailto:ann.reinhard@childrens.harvard.edu).
- ◆ Complementation analysis via retrovirus gene transfer.
- ◆ Fundamental research in DNA repair pathways, induced pluripotent stem cells and gene therapy.
- ◆ Referral for pre-implantation genetic diagnosis services at two sites in Boston if we find disease causing mutations.

### **Children's Hospital Los Angeles, Keck School of Medicine**

#### **University of Southern California**

4650 Sunset Boulevard, MS #62

Los Angeles, CA 90027

- **Neena Kapoor, MD**, Division of Research Immunology & Bone Marrow Transplant  
Telephone: 323-361-2546 Fax: 323-361-8068  
E-mail: [nkapoor@chla.usc.edu](mailto:nkapoor@chla.usc.edu)

## BONE MARROW FAILURE, cont'd

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

9300 Valley Children's Place  
Madera, California 93636

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

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

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

#### **Services Offered:**

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

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

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

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

#### **Services Offered:**

- ◆ Evaluation of new and previously diagnosed patients;
- ◆ Personalized treatment regimens and coordination of care by specialists in hematology, bone marrow transplantation, cardiology, endocrinology, genetics, gastroenterology, nephrology, urology, orthopedics, social work;

*(Continued on the next page)*

## BONE MARROW FAILURE, cont'd

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

- ◆ Stem cell collection, storage, and infusion;
- ◆ Expertise in matched sibling donor, unrelated donor, and haploidentical (alternative donor) transplantation for Fanconi anemia;
- ◆ Collaborations with Fred Hutchinson Cancer Research Center and Memorial Sloan-Kettering Cancer Center in alternative donor clinical trials.

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

3333 Burnet Ave.

Cincinnati, OH 45229

*www.cincinnatichildrens.org*

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

*(Continued on the next page)*

## BONE MARROW FAILURE, cont'd

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

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

#### Services Offered:

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

## BONE MARROW FAILURE, cont'd

### City Of Hope

1500 E. Duarte Rd.

Duarte, CA 91010

Telephone: 626-301-8442

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

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

### Services Offered:

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

### Cohen Children's Medical Center of New York

#### Bone Marrow Failure Program

Division of Hematology/Oncology and Stem Cell Transplantation

269-01 76th Ave., Rm. 225

New Hyde Park, New York 11040

- **Adrianna Vlachos, MD**, Assistant Professor of Pediatrics, Head, Bone Marrow Failure Program and Associate Head, Stem Cell Transplant Program  
Telephone: 718-470-3611 Fax: 718-343-2961  
E-mail: [avlachos@lij.edu](mailto:avlachos@lij.edu)

(Continued on the next page)

## BONE MARROW FAILURE, cont'd

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

- **Johnson M. Liu, MD**, Les Nelkin Professor of Pediatrics, Head, Section of Experimental Hematology and Les Nelkin Memorial Pediatric Oncology Research Laboratory  
Telephone: 718-470-7174  
E-mail: [jliu3@nshs.edu](mailto:jliu3@nshs.edu)
- **Jeffrey M. Lipton, MD, PhD**, Professor of Pediatrics, Chief, Division of Hematology/Oncology and Stem Cell Transplantation  
Telephone: 718-470-3460  
E-mail: [jlipton@lij.edu](mailto:jlipton@lij.edu)
- **Nancy Barbach, CSW**  
E-mail: [nbarbach@nshs.edu](mailto:nbarbach@nshs.edu)

#### Services Offered:

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

### Dana-Farber Cancer Institute

450 Brookline Avenue  
Boston, MA 02215

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

#### Services Offered:

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

## BONE MARROW FAILURE, cont'd

### Fred Hutchinson Cancer Research

#### Center

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

### Seattle Children's Hospital

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

- **Akiko Shimamura, MD, PhD**, Director, Marrow Failure Program, Pediatric Hematology-Oncology, Seattle Children's Hospital, Associate Member, Fred Hutchinson Cancer Research Center Associate Professor of Pediatrics, University of Washington School of Medicine  
Telephone: 206-667-1127 Fax: 206-667-5255  
E-mail: [ashimamu@fhcrc.org](mailto:ashimamu@fhcrc.org)
- **Hans-Peter Kiem, MD**, Member, Fred Hutchinson Cancer Research Center, Investigator, Markey Molecular Medicine Center, Adjunct Associate Professor of Pathology, Associate Professor of Medicine, University of Washington School of Medicine  
Telephone: 206-667-4425 Fax: 206-667-6124  
E-mail: [hkiem@fhcrc.org](mailto:hkiem@fhcrc.org)
- **K. Scott Baker, MD, MS**, Member and Director, Pediatric Blood and Marrow Transplantation and Survivorship Programs, Fred Hutchinson Cancer Research Center and Seattle Children's Hospital. Professor of Pediatrics, University of Washington School of Medicine.  
Telephone: 206-667-5594 Fax: 206-667-5899  
E-mail: [ksbaker@fhcrc.org](mailto:ksbaker@fhcrc.org)
- **Ann Woolfrey, MD**, Director, Unrelated Donor Program, Associate Member, Fred Hutchinson Cancer Research Center, Associate Professor of Pediatrics, University of Washington School of Medicine, Pediatric Hematopoietic Cell Transplant Program  
Telephone: 206-667-4453 Fax: 206-667-4310  
E-mail: [awoolfre@fhcrc.org](mailto:awoolfre@fhcrc.org)
- **Jennifer Adair, PhD**, Clinical Research Associate, Fred Hutchinson Cancer Research Center  
Telephone: 206-667-7110 Fax: 206-667-6124  
Email: [jadair@fhcrc.org](mailto:jadair@fhcrc.org)
- **Pam Becker, MD, PhD**, Associate Professor of Medicine, University of Washington School of Medicine, Department of Hematology  
Telephone: 206-288-2294 Fax: 206-543-3560
- **Jean Sanders, MD**, Member, Fred Hutchinson Cancer Research Center, Professor of Pediatrics, University of Washington School of Medicine.  
Telephone: 206-667-4348 Fax: 206-667-5899

#### Services Offered:

- ◆ Evaluation of new and previously diagnosed patients;
- ◆ Complementation group analysis (research basis);
- ◆ Personalized treatment regimens by specialists in hematology, bone marrow transplantation, cardiology, endocrinology, genetics, gastroenterology, nephrology, urology, orthopedics, social work;
- ◆ Gene therapy trial; Fanconi anemia repository for samples and data;
- ◆ Stem cell collection, storage, and reinfusion;
- ◆ Expertise in matched sibling donor, unrelated donor, and haploidentical (alternative donor) transplantation for Fanconi anemia;
- ◆ Collaborator, Hospital de Clinicas, University of Parana, Brazil (Carmem Bonfim, MD and Ricardo Pasquini, MD, PhD).

## BONE MARROW FAILURE, cont'd

### Hackensack University Medical Center

#### Tomorrow's Children Institute

30 Prospect Ave.

Hackensack, NJ 07601

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

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

#### Services Offered:

- ◆ Diagnosis and genetic counseling;
- ◆ Comprehensive medical treatment including Gynecology and ENT specialists;
- ◆ Matched sibling and unrelated donor transplants.

### International Fanconi Anemia Registry (IFAR)

The Rockefeller University

Laboratory of Genome Maintenance

1230 York Ave., Box 182

New York, NY 10065

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

#### Genetic Services on Research Protocol:

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

#### Testing Services on Research Protocol:

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

(Continued on the next page)

## BONE MARROW FAILURE, cont'd

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

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

- **Farid Boulad, MD**  
Memorial Sloan-Kettering Cancer Center, New York, NY  
Telephone: 212-639-6684 Fax: 212-717-3555  
E-mail: [bouladf@mskcc.org](mailto:bouladf@mskcc.org)
- **Stella Davies, MBBS, PhD, MRCP**  
Cincinnati Children's Hospital Medical Center, Cincinnati, OH  
Telephone: 513-636-1371 Fax: 513-636-3459  
E-mail: [stella.davies@cchmc.org](mailto:stella.davies@cchmc.org)
- **Margaret L. MacMillan, MD**  
University of Minnesota, Minneapolis, MN  
Telephone: 612-626-2778 Fax: 612-626-2815  
E-mail: [macmi002@umn.edu](mailto:macmi002@umn.edu)
- **David I. Kutler, MD**  
Head and Neck Surgeon  
Weill Cornell Medical Center/New York Presbyterian Hospital, New York, NY  
Telephone: 646-962-4323 646-962-0100  
E-mail: [dik2002@med.cornell.edu](mailto:dik2002@med.cornell.edu)

### Memorial Sloan-Kettering Cancer Center

1275 York Ave.

New York, NY 10021

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

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

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## BONE MARROW FAILURE, cont'd

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

#### Services Offered:

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

### Mount Sinai School of Medicine

Novel Therapeutics and Stem Cell Transplantation Program

Division of Hematology-Oncology

Annenberg 24-42, Box 1079

One Gustave L. Levy Pl.

New York, NY 10029

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

#### Services Offered:

- ◆ Adult and pediatric FA patients can be seen by specialists in adult medicine and pediatrics;
- ◆ Complete hematologic evaluation/treatment and cancer surveillance;
- ◆ Recommendations for stem cell transplantation (related and unrelated donor) at Mount Sinai School of Medicine and elsewhere.

## BONE MARROW FAILURE, cont'd

### National Cancer Institute

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

6120 Executive Blvd., Executive Plaza South, Room 7020

Rockville, MD 20892-7231

[www.marrowsfailure.cancer.gov](http://www.marrowsfailure.cancer.gov)

- **Lisa Leathwood, RN, BSN**, Research Nurse and Study Coordinator  
Telephone: 301-212-5250 and 800-518-8474 Fax: 301-212-5281  
E-mail: [lisaleathwood@westat.com](mailto:lisaleathwood@westat.com)
- **Blanche P. Alter, MD, MPH, FAAP**  
Telephone: 301-402-9731 Fax: 301-212-5281  
E-mail: [alterb@mail.nih.gov](mailto:alterb@mail.nih.gov)
- **Neelam Giri, MD, FAAP**  
Telephone: 301-594-7642 Fax: 301-212-5281  
E-mail: [ginin@mail.nih.gov](mailto:ginin@mail.nih.gov)
- **Pamela Stratton, MD**, Chief, Gynecology Consult Service  
Telephone: 301-496-9079 Fax: 301-480-6703  
E-mail: [stratton@nih.gov](mailto:stratton@nih.gov)
- **Carter Van Waes, MD, PhD**, Chief Head and Neck Surgery Branch; Clinical Director, National Institute on Deafness and other Communication Disorders  
Telephone: 301-402-4216 Fax: 301-402-1140  
E-mail: [vanwaesc@nidcd.nih.gov](mailto:vanwaesc@nidcd.nih.gov)

### Services Offered:

- ◆ Comprehensive clinical evaluation by all subspecialties;
- ◆ All clinical laboratory tests;
- ◆ Cancer screening, age and sex appropriate, such as head, neck and esophagus, and gynecological;
- ◆ Bone marrow aspirate, biopsy, and cytogenetics;
- ◆ Chromosome breakage studies in a CLIA-certified clinical laboratory;
- ◆ Genetic counseling and mutation analysis in a CLIA-certified clinical laboratory;
- ◆ Comprehensive evaluation of all immediate family members (with the exception of bone marrow studies);
- ◆ Epidemiologic study of cancer in patients and in family members.

## BONE MARROW FAILURE, cont'd

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

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

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

#### Services Offered:

- ◆ Diagnostic evaluation and genetic counseling for FA and other marrow failure syndromes;
- ◆ Comprehensive medical treatment;
- ◆ Stem cell transplantation;
- ◆ Research studies investigating molecular diagnostics, cytogenetics, complementation group subtyping, leukemogenesis, and genetics of Fanconi anemia.

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

Hematology Clinic  
770 Welch Road, Suite 261  
Palo Alto, CA 94304  
[www.lpch.org](http://www.lpch.org)

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

Hematology/Oncology Telephone: 650-723-5535

- **Bertil Glader, MD, PhD**, Professor, Pediatrics and Pathology  
E-mail: [bglader@stanford.edu](mailto:bglader@stanford.edu)
- **Michael Jeng, MD**, Associate Professor, Pediatrics  
E-mail: [mjeng@stanford.edu](mailto:mjeng@stanford.edu)
- **Wendy Wong, MD**, Clinical Assistant Professor, Pediatrics  
E-mail: [wendy.wong@stanford.edu](mailto:wendy.wong@stanford.edu)
- **Judith Lea, RN, MSN, PNP**, Hematology Nurse Practitioner  
E-mail: [jlea@lpch.org](mailto:jlea@lpch.org)
- **Kirsten Mouradian, RN, MSN, FNP**, Hematology Nurse Practitioner  
E-mail: [kmouradian@lpch.org](mailto:kmouradian@lpch.org)

(Continued on the next page)

## BONE MARROW FAILURE, cont'd

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

Stem Cell Transplant Telephone: 650-725-9250

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

#### Services Offered:

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

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

MMC 366, University of Minnesota

420 Delaware St., S.E.

Minneapolis, MN 55455

Telephone: 612-273-2800

[www.bmt.umn.edu/disease/fanconi-anemia](http://www.bmt.umn.edu/disease/fanconi-anemia)

- **John E. Wagner, MD**, Fanconi Anemia Comprehensive Care Program Leader, Director, Division of Hematology/Oncology and Blood and Marrow Transplantation, CCRF/Hageboeck Family Chair in Pediatric Oncology & Clinical Director, Stem Cell Institute  
Telephone: 612-626-2961 Fax: 612-626-4074  
E-mail: [wagne002@umn.edu](mailto:wagne002@umn.edu)
- **Margaret L. MacMillan, MD**, Fanconi Anemia Comprehensive Care Program Leader, Associate Professor, Department of Pediatrics, Division of Blood and Marrow Transplantation  
Telephone: 612-626-2778 Fax: 612-626-2815  
E-mail: [macmi002@umn.edu](mailto:macmi002@umn.edu)
- **Jakub Tolar, MD, PhD**, Director, Stem Cell/Gene Therapies, Albert and Eva Corniea Chair, Associate Professor, Department of Pediatrics, Division of Blood and Marrow Transplantation  
Telephone: 612-625-2912; Fax: 612-624-3913  
Email: [tolar003@umn.edu](mailto:tolar003@umn.edu)
- **Anna Petryk, MD**, Pediatric Endocrinology  
Telephone: 612-624-5409 Fax: 612-626-5262  
E-mail: [petry005@umn.edu](mailto:petry005@umn.edu)

(Continued on the next page)

## BONE MARROW FAILURE, cont'd

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

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

#### Services Offered:

- ◆ The University of Minnesota Fanconi Anemia Comprehensive Care Program (FACCP) utilizes a multidisciplinary team approach to ensure that the care we provide is individually tailored to meet the unique needs of each patient and family.
- ◆ The FACCP is composed of expert health care providers who specialize in blood and marrow transplantation, hematology, cancer (head and neck, gynecological), infectious disease, neurology, nephrology, cardiology, care partners (volunteer family support), social work, genetics, voice reconstruction (to treat androgen side effects), nutrition therapy, orthopedic surgery, endocrinology (diabetes, short stature), dietician, gastroenterology, gynecology and fertility counseling, and radiation therapy;
- ◆ Consultations with new and previously diagnosed Fanconi anemia patients;
- ◆ Individualized treatment planning for newly diagnosed children and adults who do not need transplant;
- ◆ Blood and marrow transplantation: expertise in unrelated marrow and umbilical cord transplantation and matched sibling donor transplantation for Fanconi anemia with a 24-bed pediatric inpatient unit and a 30-bed adult inpatient unit and state of the art outpatient bone marrow transplantation clinic;
- ◆ Genetic counseling and coordination of complementation group analysis, mutation screening, somatic mosaicism studies, and other genetic testing options including prenatal genetic testing and pre-implantation genetic diagnosis (PGD);

(Continued on the next page)

## BONE MARROW FAILURE, cont'd

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

- ◆ Family support services including nurse coordination, social work, genetic counseling, care-partners, and child and family life specialists to assist families throughout the diagnostic, transplantation, and post-transplantation processes;
- ◆ Family umbilical cord blood banking;
- ◆ Ongoing research in stem cell biology, mosaicism, genetic correction of stem cells, mechanisms of bone marrow failure, and novel treatments with collaborators around the country.

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

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

#### To Contact us:

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

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

#### Nurse Coordinator:

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

#### Medical Staff:

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

#### Services Offered:

- ◆ Consultation and education for new and previously diagnosed patients and their families;
- ◆ Comprehensive clinical management of pediatric Fanconi anemia patients;
- ◆ Stem cell transplantation for Fanconi anemia; stem cell collection and reinfusion;
- ◆ Disease based follow up post transplantation for Fanconi anemia;
- ◆ Coordinated referral to institutional subspecialists in cardiology, endocrinology, gastroenterology, nephrology, hand and orthopedic surgery interested in the unique needs of persons with Fanconi anemia; and
- ◆ Psychology, Social Work, Physical and Occupational Therapy services.

# BONE MARROW DONOR REGISTRIES

## **DKMS Americas**

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

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

### **DKMS:**

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

## **National Marrow Donor Program®**

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

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

### **Services Offered:**

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

## CORD BLOOD REGISTRIES

### **Cord Blood Registry®**

Designated Treatment Program (DTP)

Cord Blood Registry

1200 Bayhill Drive, 3rd Floor

San Bruno, CA 94066

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

Telephone: 1-888-932-6568

Cord Blood Registry® (CBR) is the world's largest and most experienced family cord blood & tissue stem cell bank. Families wishing to store their newborn's umbilical cord blood stem cells for a family member diagnosed with a life-threatening disease treatable by donor stem cells (including Fanconi anemia) are encouraged to apply for CBR's Designated Treatment Program. If eligible, CBR will provide the collection kit and process and store the newborn's cord blood and cord tissue sample for 5 years without any cost to the family. The family member must be a first-degree blood relative (full-sibling or parent) to the newborn and have an oncologist/hematologist or other treating physician agree that the stem cells can be used for treatment.

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

## ENDOCRINOLOGY

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

3333 Burnet Ave.

Cincinnati, OH 45229

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

## ENDOCRINOLOGY, cont'd

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

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

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

## GASTROENTEROLOGY

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

3333 Burnet Ave.  
Cincinnati, OH 45229

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

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

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

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

## GENETIC COUNSELING

### **Rockefeller University**

1230 York Avenue Box 182  
New York, NY 10065

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

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

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

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

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

## GYNECOLOGY

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

3333 Burnet Ave.  
Cincinnati, OH 45229

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

### Eunice Kennedy Shriver National Institute of Child Health and Human Development

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

- **Pamela Stratton, MD**, Chief, Gynecology Consult Service, Program in Reproductive and Adult Endocrinology  
Telephone: 301-496-9079 Fax: 301-480-6703  
E-mail: [Stratton@nih.gov](mailto:Stratton@nih.gov)

### Memorial Sloan-Kettering Cancer Center

1275 York Ave.  
New York, NY 10021

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

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

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

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

## HAND SURGEONS

**Ann Van Heest, MD, Professor**

- **University of Minnesota, Department of Orthopaedic Surgery**  
2450 Riverside Avenue, Rm R200  
Minneapolis, MN 55454  
Telephone 612-273-8086  
E-mail: *vanhe003@umn.edu*
- **Gillette Children's Specialty Healthcare**  
200 University Avenue East  
St. Paul, MN 55101  
Telephone: 651-291-2848
- **Shriners Hospital for Children, Twin Cities Unit**  
2025 East River Parkway  
Minneapolis, MN 55414  
Telepone: 612-596-6100

### **Services Offered:**

- ◆ Hand and upper extremity surgery in the pediatric population

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

3333 Burnet Ave.

Cincinnati, OH 45229

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

### **Shriners Hospital for Children**

3551 North Broad St.

Philadelphia, PA 19140

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

*(Continued on the next page)*

## HAND SURGEONS, cont'd

### Shriners Hospital for Children, cont'd

- **Maureen Fulcher**, Nurse Assistant  
Telephone: (215) 430-4204  
E-mail: [mfulcher@shrinenet.org](mailto:mfulcher@shrinenet.org)

#### Services Offered:

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

## OPHTHALMOLOGY

### Boston Foundation for Sight

464 Hillside Ave., Suite 205  
Needham, MA 02494  
[www.bostonsight.org](http://www.bostonsight.org)

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

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

#### Services Offered:

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

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

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

3333 Burnet Ave.

Cincinnati, OH 45229

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

## Cornell University, Weill Medical College

Department of Otolaryngology-Head and Neck Surgery

1305 York Avenue, 5th Floor

New York, NY 10021

- **David Kutler, MD**, Associate Professor  
Telephone: 646-962-4323  
E-mail: [dik2002@med.cornell.edu](mailto:dik2002@med.cornell.edu)

**Clinical Interests:** Head & Neck Cancer in Fanconi Anemia Patients, Tongue Cancer, Disorder of Nasal Sinus, Skull Base Surgery, Pharynx, Thyroid Cancer, Benign Tumor of Oral Cavity, Thyroid Surgery, Head and Neck Cancer Surgery, and Salivary Disorder.

## Johns Hopkins Medical Institutions

601 N. Caroline Street, 6th Floor

Baltimore, MD 21287-0910

- **Joseph Califano, MD**, Professor, Otolaryngology, Head & Neck Surgery & Head & Neck Research Division  
Telephone: 410-955-6420 Fax: 410-955-8510  
E-mail: [jcalifa@jhmi.edu](mailto:jcalifa@jhmi.edu)

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

## Memorial Sloan-Kettering Cancer Center

1275 York Ave.  
New York, NY 10021

- **Bhuvanesh Singh, MD, PhD**, Head and Neck Cancer  
Telephone: 212-639-2024  
E-mail: [singhb@mskcc.org](mailto:singhb@mskcc.org)

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

## National Institutes of Health

NIDCD/NIH  
10 Center Drive, Building 10  
Bethesda, MD 20892

- **H. Jeffrey Kim, MD**, Senior Staff Clinician, Head and Neck surgery Branch, National Institute on Deafness and other Communication Disorders, NIH, Associate Professor, Department of Otolaryngology (Ears, Nose, Throat), Head and Neck Surgery, Georgetown University Hospital  
Telephone: 301-496-5369 Fax: 301-402-0409  
E-mail: [kimj@nidcd.nih.gov](mailto:kimj@nidcd.nih.gov)

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

- **Carter Van Waes, MD, PhD**, Chief Head and Neck Surgery Branch; Clinical Director, National Institute on Deafness and other Communication Disorders  
Telephone: 301-402-4216 Fax: 301-402-1140  
E-mail: [vanwaesc@nidcd.nih.gov](mailto:vanwaesc@nidcd.nih.gov)

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

## University of Chicago Medical Center

5841 S. Maryland Avenue  
Chicago, IL 60634

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

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

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

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

## University of Cincinnati, College of Medicine

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

- **Keith A. Casper, MD**, Assistant Professor  
Telephone: 513-558-1890 Fax: 513-558-4477  
E-mail: [Keith.casper@uc.edu](mailto:Keith.casper@uc.edu)
- **Keith M. Wilson, MD**
- **Lee A. Zimmer, MD**

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

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

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

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

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

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

Suite 300

203 Lothrop Street

Pittsburgh, PA 15213

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

**Specialty:** Otolaryngology

**Sub Specialty:** Head & Neck Surgery

### University of Texas MD Anderson Cancer Center

1515 Holcombe Blvd., Unit 441

Houston, TX 77030

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

**Clinical Interests:** Head & Neck Cancer, Salivary Carcinoma, and Thyroid Cancer, Human Papillomavirus, and Sarcomas of the Head and Neck

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

# PRE-IMPLANTATION GENETIC DIAGNOSIS

## The Genesis Genetics Institute, Genomic Technology Center

Genomics Center at Samaritan - A1100

5555 Conner

Detroit, MI 48213

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

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

### Services Offered:

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

## The Reproductive Genetics Institute

2825 N Halsted St.

Chicago, IL 60657

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

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

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

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

### Services Offered:

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

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

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

## US Fanconi Anemia Testing Resources

Institution	Test
<b>Cincinnati Children’s Hospital Medical Center Fanconi Anemia Comprehensive Care Center Bone Marrow Failure Clinic</b> Cincinnati, OH • Robin Mueller, BSN, RN, CPN Care Manager 513-636-3218 Toll-free: 1-800-344-2462, ext. 3218 <i>robin.mueller@chmcc.org</i>	DEB/MMC diagnostic testing using blood or bone marrow samples
	Complementation analysis for <i>A, B, C, E, F, G, J, L, I</i> ( <i>I</i> analysis via skin testing only) and <i>FANCD2</i> (via western blot). Testing done with blood, bone marrow, or skin biopsy samples. Note: This testing must be requested by clinicians or researchers.
	Molecular testing to find specific mutations for patients with <i>FANCA, FANCC, or FANCG</i>
	Prenatal diagnostic molecular testing for <i>FANCA, FANCC, or FANCG</i>
	Carrier detection testing for patients with a family history of FA, from complementation groups <i>FANCA, FANCC, or FANCG</i>
<b>Dana-Farber Cancer Institute</b> Boston, MA • Alan D’Andrea, MD 617-632-2080 <i>alan_dandrea@dfci.harvard.edu</i> • Lisa Moreau, MS 617-632-6302 <i>lisa_moreau@dfci.harvard.edu</i>	DEB/MMC diagnostic testing using blood, bone marrow, or skin fibroblasts
	<i>FANCD2</i> western blot (Research)
<b>Indiana University School of Medicine Wells Center, Riley Hospital for Children</b> Indianapolis, IN • Helmut Hanenberg, MD 317-278-9290 or 274-2980 Fax 317-274-2852 <i>hhanenbe@iupui.edu</i>	Complementation Group (Research): Use of retroviruses for <i>A, B, C, D2, E, F, G, I, J, L, M, N, O, P</i> in primary T-cells, bone marrow or fibroblast cells or in lymphoblast cell lines (LCL)
	<i>FANCD2</i> Western Blotting (Research)
<b>Indiana University School of Medicine Cytogenetic Lab, Dept. of Medical &amp; Molecular Genetics</b> Indianapolis, IN • Gail H. Vance, MD 317-274-2243 Fax 317-278-1616 <i>ghvance@iupui.edu</i>	Diagnostic testing: Cytogenetic breakage studies with DEB on peripheral blood and fibroblast cultures— <i>CLIA-certified</i>
	Mutation testing for <i>FANCA, FANCC, FANCG</i> Collaborative mutation testing and research with Gail Vance, MD, and Shaochun Bai, PhD, Medical & Molecular Genetics, Indianapolis

Institution	Test
<b>Oregon Health &amp; Science University</b> Portland, OR • Susan Olson, PhD, FACMG (cytogenics) 503-494-5964 <i>olsonsu@ohsu.edu</i> • Markus Grompe, MD (complementation) 503-494-6888 <i>grompem@ohsu.edu</i> • C. Sue Richards, PhD, FACMG (molecular) 503-494-5400 <i>richarsu@ohsu.edu</i>	DEB/MMC diagnostic testing
	Complementation group (Research)
	Mutation Analysis for A, C, G, E, F (Please see GeneTests for further information at <i>geneclinics.org</i> )
<b>Quest Diagnostics</b> Chantilly, VA • Aimee Martin, MGC, CGC 800-336-3718, ext. 7148 <i>aimee.d.martin@questdiagnostics.com</i> • Dr. Steven Schonberg 800-336-3718 x7285	DEB diagnostic testing: <b>the doctor needs to specify DEB test, otherwise it is possible that a DNA carrier test for FANCC may be done.</b>
	Mutation analysis for FANCC (IVS4+4A>T)
	Prenatal diagnosis
<b>Quest Diagnostics, San Juan Capistrano, CA</b> • Joy Redman, MS, MBA, CGC 800-642-4657, ext. 4279 <i>Joy.B.Redman@questdiagnostics.com</i>	Mutation analysis for FANCC (IVS4+4A>T and 322delG)

**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>
  - 1) Select "Gene Reviews"
  - 2) Select "Search by Disease"
  - 3) Enter "Fanconi anemia" into the text box



# International 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.

## AUSTRALIA

### The Children's Hospital at Westmead

Sydney, NSW 2145 Australia

[www.chw.edu.au/prof/services/fanconi\\_anaemia](http://www.chw.edu.au/prof/services/fanconi_anaemia)

- **Dr. Julie Curtin, MD, PhD**, Head Haematology Department  
Telephone: 612- 9845-0000 Fax 612-9845-3332  
E-mail: [juliec@chw.edu.au](mailto:juliec@chw.edu.au)
- **Professor Peter Shaw**, Head BMT Service  
Telephone: 612-9845-0000 Fax: 612-9845-2171  
E-mail: [peters@chw.edu.au](mailto:peters@chw.edu.au)
- **Ida O'Brien**, Clinical Nurse Consultant BMT Follow Up  
Telephone: 612- 9845-0000 Fax: 612-9845-2171  
E-mail: [Idao1@chw.edu.au](mailto:Idao1@chw.edu.au)
- **A/Prof. Meredith Wilson**, Clinical Geneticist  
Telephone: 612-9845-3273 Fax: 612-9845-3204  
E-mail: [merediw@chw.edu.au](mailto:merediw@chw.edu.au)
- **A/Prof. David Little**, Director Orthopaedic Research  
Telephone: 612- 9845-3352 Fax: 612- 9845-3180  
E-mail: [DavidL3@chw.edu.au](mailto:DavidL3@chw.edu.au)
- **Professor Chris Cowell**, Head Endocrinology Department  
Telephone: 612-9845-0000 Fax: 612-9845-3170  
E-mail: [chrisc@chw.edu.au](mailto:chrisc@chw.edu.au)
- **Dr. Carsten E. Palme, FRACS**, Surgeon, Otolaryngology Head & Neck Surgery  
Telephone: 612-9845-6025 Fax: 612-9893-7440 Department of Surgery, Westmead Hospital  
E-mail: [Carsten\\_Palme@wsahs.nsw.gov.au](mailto:Carsten_Palme@wsahs.nsw.gov.au)
- **Mark Schifter**, Oral Medicine and Oral Pathology  
Telephone: 612-9845-8716 Fax: 612-9845-5740  
E-mail: [mark\\_schifter@wsahs.nsw.gov.au](mailto:mark_schifter@wsahs.nsw.gov.au)

### Services Offered:

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

- ◆ Diagnostic testing and screening of siblings;
- ◆ Genetic counselling; 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;

(Continued on the next page)

## **AUSTRALIA, cont'd**

### **The Children's Hospital at Westmead, cont'd**

- ◆ 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

- **Tina Carter, FRACP, PhD**, Clinical Director of Bone Marrow Transplantation Program  
Telephone: 08-9340-8222  
E-mail: [Tina.Carter@health.wa.gov.au](mailto:Tina.Carter@health.wa.gov.au)

### **Sydney Children's Hospital**

Cord & Marrow Transplant Program

High Street Randwick, 2031

Sydney, NSW Australia

- **Tracey O'Brien, FRACP, MBChB, MHL, BSc**, Program Director, Paediatric and Adolscnt Oncologist/Hematologist  
Telephone: 61-2-93821733 Fax: 61-2-93821789  
E-mail: [Tracey.O'Brien@sesiahs.health.nsw.gov.au](mailto:Tracey.O'Brien@sesiahs.health.nsw.gov.au)

#### **Services Offered:**

Sydney Children's Hospital is a large tertiary pediatric hospital. Over 750 pediatric transplants have been performed at the center since establishment of the transplant program in 1975. The center is considered a national leader in unrelated marrow and cord transplants with particular interest in transplant for non-malignant diseases. The center director has specialized training and expertise in treatment of Fanconi anemia offering a well established multi-disciplinary comprehensive pre- and post-transplant service for patients with FA.

## BRAZIL

### Hospital de Clinicas, University of Parana

Serviço 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 of Fanconi Anemia Outpatient Clinic  
Telephone: 55-41-3360-1000 Fax 55-41-3360-1015  
E-mail: *carmembonfim@gmail.com*
- **Ricardo Pasquini, MD, PhD**, Senior Professor, Federal University of Parana  
Telephone: 55-41-3360-1000 Fax: 55-41-3360-1015  
E-mail: *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.
- ◆ Mutation analysis ( *FANCA*, C and G) and *FANCD2* by western blot.

## CANADA

### The Hospital for Sick Children, The University of Toronto

555 University Avenue  
Toronto, Ontario, Canada M5G 1X8

- **Yigal Dror, MD, FRCP(C)**, Associate Professor of Paediatrics; Director, Marrow Failure and Myelodysplasia Program; Division of Hematology/Oncology; Scientist, Program in Cell Biology, Research Institute  
Telephone: (416) 813-5630 Fax: (416) 813-5327  
E-mail: *yigal.dror@sickkids.ca*
- **John Doyle, MD**, Associate Professor of Paediatrics; Section Head, Section of Blood & Marrow Transplant, Division of Hematology/Oncology  
Telephone: (416) 813-6906  
E-mail: *john.doyle@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  
E-mail: *adam.gassas@sickkids.ca*

(Canada continued on the next page)

## CANADA, cont'd

### Princess Margaret Hospital

Ontario Cancer Institute  
University of Toronto  
610 University Ave  
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  
E-mail: [Jeff.Lipton@uhn.on.ca](mailto:Jeff.Lipton@uhn.on.ca)

## 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  
E-mail: [amaka@une.net.co](mailto:amaka@une.net.co)
- **Dr. Yadira Coll**, Pediatric Hematology  
Telephone: 57 4 3409314  
E-mail: [yacoll@une.net.co](mailto:yacoll@une.net.co)

#### Services offered:

Evaluation, medical treatment, stem cell transplantation

<b><u>Clinica Marly</u></b> Calle 50 No. 9 - 67 Bogotá, Colombia	<b><u>Clinica Colsubsidio</u></b> Carrera 24 # 63 - 50 Bogotá, Colombia	<b><u>National University of Colombia</u></b> Carrera 45 No 26-85 Building Uriel Gutierrez Bogotá, Colombia
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- **Dr. Adriana Linares**  
Telephone: (571) 343-6600 (extension 1364, 1362, or 1280)  
E-mail: [alinaresb@gmail.com](mailto:alinaresb@gmail.com)

#### Services Offered:

Pediatric hematology oncology, clinical evaluation, medical treatment and therapy, stem cell transplantation

## COLOMBIA, cont'd

### HematoOncologos S.A.

Calle 5B 5 #38-10

Cali, Valle

Colombia

- **Oscar Ramirez W. MD MPhil**  
Telephone: +57-2-5561588 or mobile 317-4315011  
E-mail: *oramirez1167@gmail.com* or *hopediatria@hematooncologos.com*

#### **Services Offered:**

Pediatric hematology oncology, Hematopathology, clinical evaluation, medical therapy, stem cell transplantation related and unrelated

## DENMARK

### University Hospital of Aarhus at Skejby

Brendstrupgaardsvej 100

DK-8200 Aarhus N

DENMARK

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

#### **Services Offered:**

- ◆ Diagnosis, treatment and follow-up for children with Fanconi anemia.

# FRANCE

## Hôpital Robert DEBRE

48, boulevard Sérurier  
75935 Paris cedex 19  
FRANCE

- **Thierry Leblanc, MD**, Department of Pediatric Hematology .  
Telephone direct: 33-1-4003-4185 Secretary: 33-1-7128-2535 Fax: 33-1-4003-4740  
E-mail: [thierry.leblanc@rdb.aphp.fr](mailto: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  
E-mail: [jean-hugues.dalle@rdb.aphp.fr](mailto: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  
E-mail: [gerard.socie@sls.aphp.fr](mailto:gerard.socie@sls.aphp.fr)
- **Thierry Leblanc, MD**, Department of Pediatric Hematology  
Telephone direct: 33-1-4249-9725 Secretary: 33-1-4249-9721 Fax: 33-1-4249-9823  
E-mail: [thierry.leblanc@sls.aphp.fr](mailto:thierry.leblanc@sls.aphp.fr)
- **Jean Soulier, MD, PhD**, Genome Rearrangements and Cancer Group, Hematology Laboratory  
Telephone: 33-1-4249-9891 Fax: 33-1-4249-4027  
E-mail: [jean.soulier@sls.aphp.fr](mailto:jean.soulier@sls.aphp.fr)
- **Arnaud Rigolet, MD**, Department of Oral and Maxillofacial Surgery  
Telephone: 33-1-42-49-41-92 Fax: 33-1-1-49-49-91-92  
E-mail: [arnaud.rigolet@sls.aphp.fr](mailto:arnaud.rigolet@sls.aphp.fr)

## FRANCE, cont'd

### Hôpital Saint-Louis, cont'd

#### 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

- **Wolfram H. Ebell, MD**  
Telephone: 49-30-450-566-014 Fax: 49-30-450-566-919  
E-mail: [wolfram.ebell@charite.de](mailto:wolfram.ebell@charite.de)

#### Services Offered:

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

### 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: 49-211-811-7662 Fax: 49-211-811-7634  
E-mail: [velleuer@uni-duesseldorf.de](mailto: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  
E-mail: [lesch@med.uni-duesseldorf.de](mailto:lesch@med.uni-duesseldorf.de)

(Germany continued on the next page)

## GERMANY, cont'd

### Heinrich Heine University Medical Center, cont'd

#### Services Offered:

- ◆ Cooperation with Ruud Brakenhoff, University of Amsterdam, on "Progression of FA-SCC and Development of a Non-Invasive Screening Method for Precursor Lesions";
- ◆ Close cooperation with the two German FA family support groups: Deutsche FA-Hilfe e.V. (Ralf Dietrich) and Aktionskreis Fanconi Anemia e.V.

### 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  
E-mail: [Rupert.Handgretinger@med.uni-tuebingen.de](mailto: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;
- ◆ Cotransplantation of bone marrow with mesenchymal stem cells (MSC) to enhance engraftment and to prevent Graft-versus-Host-Disease (GvHD);
- ◆ Extracorporeal photopheresis (ECP) 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

[refain@vsnl.net](mailto:refain@vsnl.net)

- **Sheila Mohan, MBBS, DCH, PhD**  
Telephone: 91-44-2491-2943 Mobile: 91-92-8211-4661
- **Revathi Raj, MBBS, DCH, MRCP (Path)**  
Telephone: 91-44-2433-1741, ext. 2509

## INDIA, cont'd

### Apollo Specialty Hospital, cont'd

#### 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 (in process of development);
- ◆ 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

E-mail: [vbaburao@hotmail.com](mailto:vbaburao@hotmail.com)

#### Services Offered:

- ◆ Chromosomal breakage study using MMC and DEB test;
- ◆ Cytogenic study from bone marrow and FISH analysis;
- ◆ FANCD2 western blot.

## IRAN

### Hematology-Oncology and SCT Research Center

Tehran University of Medical Sciences  
Shariati Hospital  
Kargar Ave.  
14114, Tehran, Iran  
<http://horcsct.tums.ac.ir>

- **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  
E-mail: [ghavamza@sina.tums.ac.ir](mailto:ghavamza@sina.tums.ac.ir)
- **Amir Ali Hamidieh, MD**, Assistant Professor of Medicine, Pediatric Hematologist Oncologist, Director of Fanconi Anemia Transplant Program  
Telephone: 98-21-84902645 Fax: 98-21-88004140  
E-mail: [aahamidieh@sina.tums.ac.ir](mailto:aahamidieh@sina.tums.ac.ir)

(Iran continued on the next page)

## IRAN, cont'd

### Hematology-Oncology and SCT Research Center, cont'd

#### 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, 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  
E-mail: [slavin@CTCIcenter.com](mailto: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 (NST). Stem cell transplantation can also be considered from half-matched (haploidentically mismatched) family member while avoiding the risk of graft-versus-host disease.

# ITALY

## G. Gaslini Children's Institute

Largo G.Gaslini 5  
16147 Genova, Italy

- **Carlo Dufour, MD**, Head, Hematology Unit, G. Gaslini Children's Institute  
Telephone: 39-010-5636-694 Fax: 39-010-5636-714  
E-mail: [carlodufour@ospedale-gaslini.ge.it](mailto:carlodufour@ospedale-gaslini.ge.it)
- **Johanna Svahn, MD**, Hematology Unit, G. Gaslini Children's Institute  
Telephone: 39-010-5636-694 Fax: 39-010-5636-714  
E-mail: [johanna.svahn@ospedale-gaslini.ge.it](mailto:johanna.svahn@ospedale-gaslini.ge.it)
- **Enrico Cappelli, PhD**, Hematology Laboratory, G. Gaslini Children's Institute  
Telephone: 39-010-5636-693 Fax: 39-010-5636-714  
E-mail: [enricocappelli@ospedale-gaslini.ge.it](mailto:enricocappelli@ospedale-gaslini.ge.it)

### Services Offered:

- ◆ Primary diagnosis with DEB test, Cell Cycle analysis and MMC sensitivity, D2 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, Indiana) and Dr. Juan Bueren (CIEMAT, Madrid, Spain) for remaining FA complementation group analyses;
- ◆ Collaboration with Dr. Anna Savoia, IRCSS Burlo Garofolo, University of Trieste Italy, for molecular diagnosis of FA;
- ◆ Haematopoiesis Laboratory (cell cultures, cytokine hypersensitivity tests);
- ◆ Cytogenetic Laboratory;
- ◆ Close scientific collaboration with Dr. Grover Bagby (OHSU, 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;
- ◆ 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.

*(Italy continued on the next page)*

## ITALY, cont'd

### 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  
E-mail: *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  
Isheara, Kanagawa, 259-1193, Japan

- **Hiromasa Yabe, MD**, Stem Cell Transplantation  
Telephone: 81-463-93-1121 Fax: 81-463-95-9567  
E-mail: *yabeh@is.icc.u-tokai.ac.jp*
- **Miharu Yabe, MD**, Stem Cell Transplantation  
Telephone: 81-463-93-1121 Fax: 81-463-93-8607  
E-mail: *miharu@is.icc.u-tokai.ac.jp*
- **Shunichi Kato, MD**, Stem Cell Transplantation  
Telephone: 81-463-93-1121 Fax: 81-463-91-6235  
E-mail: *skato@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;
- ◆ Umbilical cord blood bank and cell processing center.

# LEBANON

## St. George Hospital University Medical Center

Dept of Pediatrics and Pediatric Hematology/Oncology

OFFICE 117

Ashrafieh, Beirut, LEBANON

- **Dr. Roula Farah**  
Cell phone: 961-3-681-309  
E-mail: *roula.fs@dm.net.lb*

### Services Offered:

- ◆ Complete clinical evaluation, treatment and follow-up of new and previously diagnosed FA patients
- ◆ Diagnostic testing (Chromosomal breakage with Mitomycin C, Karyotype, bone marrow examination, etc.)
- ◆ 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. Inès Montero Ponce**  
E-mail: *imontero99@yahoo.com*
- **Dr. Ana Lilia Hernández Moreno**

*(Mexico continued on the next page)*

## MEXICO, cont'd

### **Prof. Dr. Clara Gorodezky**

Head of The Department of Immunology & Immunogenetics, InDRE,  
Secretary of Health

Carpio 470, México DF, 11340, México

President of the Board of The Fundacion Comparte Vida, A.C.

Tel (52 55) 5341 4569; Fax:(52 55) 5341 4418

E-mail: [clarag@unam.mx](mailto:clarag@unam.mx); [cgorodea@fundacioncompartevida.org.mx](mailto:cgorodea@fundacioncompartevida.org.mx)

[www.fundacioncompartevida.org.mx](http://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 TC abroad;
- ◆ We belong to BMDW and are a Coop Registry of NMDP.

## (THE) NETHERLANDS

### **Leiden University Medical Center**

PO Box 9600

Leiden, 2300 RC, The Netherlands

- **Elisabeth T. Korthof, MD**, Department of Pediatric Stem Cell Transplantation, Pediatric Hemato-Oncologist  
Telephone: 31-71-526-4131 Fax: 31-71-524-8198  
E-mail: [E.T.Korthof@lumc.nl](mailto:E.T.Korthof@lumc.nl)

### **UMC Utrecht**

Kinderarts - Hematoloog

Wilhelmina Kinderziekenhuis

Postbus 85090

3508 AB Utrecht

Huispostnr KC 03.063.0, The 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 The Netherlands.  
Telephone: 31 (0)88 7554344 Fax: 31 (0)88 7555350  
E-mail: [m.bierings@umcutrecht.nl](mailto:m.bierings@umcutrecht.nl)

## (THE) NETHERLANDS, cont'd

### VU University Medical Center Amsterdam

Department of Clinical Genetics  
Van der Boechorststraat 7  
NL-1081 BT Amsterdam  
The Netherlands

#### **Diagnosis:**

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

#### **Contacts:**

- **Hans Gille, PhD**  
E-mail: *jpp.gille@vumc.nl*
- **Resie Vervenne, PhD**  
E-mail: *r.vervenne@vumc.nl*
- **Aggie Nieuwint, MSc**  
Contact for chromosomal breakage testing.  
E-mail: *awm.nieuwint@vumc.nl*

#### **Research:**

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

#### **Contacts:**

- **Josephine C. Dorsman, PhD**  
E-mail: *jc.dorsman@vumc.nl*
- **Hans Joenje, PhD**  
E-mail: *joenje@vumc.nl*
- **Johan P. de Winter, PhD**  
E-mail: *j.dewinter@vumc.nl*

#### **Services Offered:**

##### **Diagnosis:**

- ◆ Diagnosis is 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 The Netherlands:**

- **Dr. M. Bierings, MD, PhD**, Stem Cell Transplantation, Clinical Coordinator for FA families in The Netherlands, Utrecht University Medical Center;
- **Dr. E.T. Korthoff, MD, PhD**, Stem Cell Transplantation, Leiden University Medical Center;
- **Dr. 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  
E-mail: *Siobhan.Cross@cdhb.govt.nz*

#### **Services Offered:**

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

## 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  
E-mail: *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.

## SINGAPORE

### National University Health System, Singapore

Paediatric Haematology/ Oncology/ BMT

University Children's Medical Institute

5 Lower Kent Ridge Road

Singapore 119074

Republic of Singapore

[www.nuh.com.sg/\\_kids/index.htm](http://www.nuh.com.sg/_kids/index.htm)

#### Physicians:

- **Thuan-Chong Quah, MBBS**  
E-mail: [paeqtc@nus.edu.sg](mailto:paeqtc@nus.edu.sg)
- **Allen Yeoh Eng-Juh, MBBS**  
E-mail: [paeyej@nus.edu.sg](mailto:paeyej@nus.edu.sg)
- **Poh-Lin Tan, MBBS**  
E-mail: [poh\\_lin\\_tan@nuhs.edu.sg](mailto:poh_lin_tan@nuhs.edu.sg)
- **Pei-Lin Koh, MBBS**  
E-mail: [pei\\_lin\\_koh@nuhs.edu.sg](mailto:pei_lin_koh@nuhs.edu.sg)

#### International Patient Liaison Centre:

Telephone (24hr Helpline): (65) 67792777

E-mail: [iplc@nhg.com.sg](mailto:iplc@nhg.com.sg)

#### Services Offered:

- ◆ Paediatric Haematology/ Oncology/ Blood and Marrow Transplantation;
- ◆ Paediatric Subspecialties;
- ◆ Comprehensive Laboratory Service;
- ◆ Stem Cell Laboratory.

## 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  
E-mail: [rosalind.wainwright@wits.ac.za](mailto:rosalind.wainwright@wits.ac.za)

(South Africa continued on the next page)

## **SOUTH AFRICA, cont'd**

### **Johannesburg Hospital**

Division of Haematology and Oncology  
Dept. 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, and University of the Witwatersrand**

PO Box 1038  
Johannesburg 2000  
South Africa

- **Dr. Amanda Krause**

Telephone: 27-11-489-9219/9224 Fax: 27-11-489-9226  
Email: *amanda.krause@nhls.ac.za*

#### **Services Offered (Chris-Hani Baragwanath, Johannesburg, and NHLS):**

- ◆ Genetic counseling service for families with FA;
- ◆ Diagnostic, carrier, preclinical and prenatal testing.

### **Unitas Hospital, Pretoria, Gauteng**

Dr. Charmaine Jacobs, MD  
PO Box 15225  
Lyttleton, 0140, Pretoria  
Gauteng, South Africa

- **Dr. Charmaine Jacobs, MD, Pediatric Oncology/Haematology Unit**

Telephone: 27-12-6778076 Mobile Phone: 27-82082-07435 Fax: 27-12-6647848  
E-mail: *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.

## **SOUTH AFRICA, cont'd**

### **University of the Free State**

PO Box 339(G69)  
Bloemfontein  
South Africa  
9300

- **Prof. D.K. Stones**  
Paediatric Oncology and Haematology  
Department of Paediatrics and Child Health  
Telephone: 27-51-4052820 Fax: 27-51-4443230  
E-mail: *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

- **Dr. Cristina Belendez**  
Telephone: 91-529-00-37  
E-mail: *cbelendez.hgugm@salud.madrid.org*

### **Hospital Universitario de la Princesa**

C/Doctor Esquerdo, 45  
28028 Madrid

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

*(Spain continued on the next page)*

# SPAIN, cont'd

## Hospital Vall d'Hebrón

Pediatric Oncology  
Pg Vall D'Hebrón 119-129  
Barcelona 08035

- **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  
E-mail: [jsevilla.hnjs@salud.madrid.org](mailto:jsevilla.hnjs@salud.madrid.org)

## Universitat Autònoma de Barcelona

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

- **Jordi Surrallés, PhD**, Full Professor of Genetics (UAB-CFS Scientific Director)  
Telephone: 34-935-811-830 Fax: 34-935-812-387  
E-mail: [jordi.surralles@uab.es](mailto: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  
E-mail: [MaríaRoser.Pujol@uab.cat](mailto:MaríaRoser.Pujol@uab.cat)

### Services Offered:

- ◆ DEB chromosomal breakage testing;
- ◆ Diagnosis of mosaicism;
- ◆ MMC-induced G2/M-cell phase arrest assay;
- ◆ FANCD2 monoubiquitination assay;
- ◆ Spanish contact for prenatal diagnosis;
- ◆ FA subtyping by retrovirus mediated gene transfer, in collaboration with Dr. J.A. Bueren's laboratory at CIEMAT, Madrid;
- ◆ Genetic counseling;
- ◆ Maintenance of a database integrating genetic and clinical data;

## SPAIN, cont'd

### Universitat Autònoma de Barcelona, cont'd

- ◆ Maintenance of a biobank of Spanish FA patients with cryopreserved transformed cell lines and DNA;
- ◆ An FA registry with approximately 170 (Spanish) families.

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

### İstanbul University

Bone Marrow Bank & Department of Medical Biology, Istanbul Medical Faculty  
Çapa 34390 İstanbul, 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  
E-mail: [nevinyalman@gmail.com](mailto:nevinyalman@gmail.com)

## UNITED KINGDOM

### Birmingham Children's Hospital

Steelhouse Lane  
Birmingham, West Midlands B4 6NH United Kingdom

- **Phil Darbyshire, MD**, Consultant Pediatric Hematologist  
Telephone: 44-121-333-9999  
E-mail: [Phil.Darbyshire@bch.nhs.uk](mailto:Phil.Darbyshire@bch.nhs.uk)

*(United Kingdom continued on the next page)*

## UNITED KINGDOM, cont'd

### Bristol Royal Hospital for Children

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: 44-117-3428044 Fax: 44-117-3428628  
E-mail: *colin.steward@uhbristol.nhs.uk*

#### Services Offered:

- ◆ Comprehensive diagnostic and routine haematological care in specialized clinic;
- ◆ Coordination of complementation group analysis, mutation screening, somatic mosaicism studies and other genetic testing;
- ◆ 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  
E-mail: *Josu.delaFuente@imperial.nhs.uk*

## UNITED KINGDOM, cont'd

### Yorkshire Paediatric Haematology Unit

Leeds General Infirmary  
Fanconi Anaemia - Multidisciplinary Clinic  
Great George Street  
Leeds LS1 3EX United Kingdom

- **Professor Sally E. Kinsey, MD**, Paediatric Haematologist  
Telephone: 0113-392-8191 Fax: 0113-392-8488  
E-mail: [sally.kinsey@leedsth.nhs.uk](mailto:sally.kinsey@leedsth.nhs.uk)
- **Ben Sykes**, Nurse Co-ordinator  
Telephone: 0113-392-7379 Fax: 0113-392-6629  
E-mail: [benjamin.sykes@leedsth.nhs.uk](mailto:benjamin.sykes@leedsth.nhs.uk)

#### **Services Offered:**

The Fanconi Anaemia multidisciplinary clinic provides initial general assessment of cases and confirmation of diagnosis. The multidisciplinary clinic provides direct access to specialists in: haematology, nephrology, genetics, nutrition, dentistry, psychology and life-style advice. In addition there is access to other specialists: hand surgery, hepatology, gynaecology, head and neck surgery, endocrinology and urology.

Patients are assessed and reviewed in Leeds with communication to their referring clinician. Follow up in the multidisciplinary 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 co-ordinated via their referring clinician.

Where appropriate, work-up for stem cell transplantation can be arranged in Leeds. The Yorkshire Paediatric Haematology department is a JACIE accredited Bone Marrow Transplant Unit.

# International Fanconi Anemia Testing Resources

Country	Institution	Test
Australia	<b>The Children's Hospital at Westmead</b> Sydney, Australia • Zhan he Wu, PhD 0061-2-98453236 <i>zhan.wu@health.nsw.gov.au</i>	DEB/MMC Diagnostic Testing ( <i>Accredited by the National Association of Testing Authorities, Australia</i> )
Canada	<b>Hospital for Sick Children</b> Toronto, Canada • Yigal Dror, MD (416) 813-5630 <i>yigal.dror@sickkids.ca</i>	DEB/MMC Diagnostic Testing ( <i>Licensed under the Ontario Ministry of Health and Long Term Care</i> )
		Canadian Inherited Marrow Failure Registry (Enrollment of patients on this research study includes data collection and sample repository.)
Germany	<b>Heinrich Heine University Medical Center</b> ENT (HNO) lab Düsseldorf, Germany • Helmut Hanenberg, MD +49-211-811-0832 or 0830 Fax - 0839 <i>Hanenberg@uni-duesseldorf.de</i>	Complementation Group (Research)
		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)
		FANCD2 western blot
		Collaborative mutation testing and research with Detlev Schindler, MD, Würzburg, and Christian Kratz, MD, Hannover, Germany
	<b>University of Würzburg</b> Würzburg, Germany • Detlev Schindler, MD, PhD 49-931-888-4088-4098 <i>schindler@biozentrum.uni-wuerzburg.de</i>	MMC Diagnostic Testing ( <i>Certified under Governmental and Societies</i> )
		FANCD2 Immunoblots
		Prenatal Diagnosis
		Mutation Analysis ( <i>Certified under Governmental and Societies</i> )
		Complementation Group
(The) Netherlands	<b>VU University Medical Center</b> Amsterdam, The Netherlands • Hans Gille, PhD 31-20-444-8346 <i>jgp.gille@vumc.nl</i>	Mutation Analysis FANCA ( <i>Clinically Certified</i> )
		Mutation Analysis FANCC, -E, -F, and -G ( <i>Clinically Certified</i> )
		Mutation Analysis of other FANC genes ( <i>Clinically Certified</i> )
		Prenatal DNA diagnosis ( <i>Clinically Certified</i> )

Country	Institution	Test
Serbia	<b>Laboratory for Medical Genetics Mother and Child Health Care Institute of Serbia</b> St. Radoja Dakica 6-8 11070 Belgrade, Serbia • Dr. Vukan Cupic 381-11-3108273 <i>genetikaimd@beotel.net</i>	DEB Diagnostic Testing
Spain	<b>Hematopoiesis and Gene Therapy Division, CIEMAT/ CIBER of Rare Diseases (CIBERER)</b> Madrid, Spain <i>www.ciemat.es</i> <b>Spanish Fanconi Anemia Network: <i>www.redfanconi.org</i></b> • Juan Bueren, PhD, Head of Hematopoiesis and Gene Therapy 34-91-346-6518 <i>juan.bueren@ciemat.es</i> • José A. Casado, Senior researcher 34-91-496-2525 <i>jose.casado@ciemat.es</i> • Aurora de la Cal, Secretary of the Spanish FA Research Network 34-91-496-2518 <i>aurora.delacal@ciemat.es</i>	FA subtyping by retroviral complementation (A,C,G,E,F) in T-cells. (Research)
		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 (A,C,G).
		Cellular and molecular studies in FA cells to help of diagnosis of FA patients with inconclusive DEB test (western and foci of <i>FANCD2</i> ).
		Analysis of hematopoietic reserve in bone marrow samples from FA patients (CD34+ and Colony Forming Cells).
		Spanish FA Registry
<b>Universitat Autònoma de Barcelona</b> Barcelona, Spain • Jordi Surrallés, PhD 34-935-811-830 <i>surralleslab.uab.cat</i> <i>saicro.uab.cat</i>	DEB Diagnostic Testing (Research), Diagnosis of Mosaicism	
	Mutation Analysis (Research) for Spanish Gypsy Population	

Additional testing information for Fanconi anemia is available at:

<http://geneclinics.org>

- 1) Select "Gene Reviews"
- 2) Select "Search by Disease"
- 3) Enter Fanconi anemia



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