



Fanconi Anemia  
RESEARCH FUND, INC.

International Treatment and Testing  
Resource Guide

**2011**



## 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>

#### Dana-Farber Cancer Institute

44 Binney St.  
Boston, MA 02115

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

- **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)
- **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 of Wisconsin

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

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

#### Services Offered:

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

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

3333 Burnet Ave.

Cincinnati, OH 45229

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

- **Robin Mueller, RN**, Nurse Coordinator, Fanconi Anemia Comprehensive Care Center, Division of Bone Marrow Transplantation and Immune Deficiency, Cancer and Blood Diseases Institute  
Telephone: 513-636-3218 Fax: 513-636-7951  
E-mail: [robin.mueller@cchmc.org](mailto:robin.mueller@cchmc.org)
- **Lisa Vormohr, RN**, Nurse Coordinator, Fanconi Anemia Comprehensive Care Center, Division of Bone Marrow Transplantation and Immune Deficiency, Cancer and Blood Diseases Institute  
Telephone: 513-636-3218 Fax- 513-636-7951.
- **Stella Davies, MB BS, PhD, MRCP**, Jacob G. Schmidlapp Endowed Chair and Professor of Pediatrics, University of Cincinnati College of Medicine, Director, Division of Bone Marrow Transplantation and Immune Deficiency, Cancer and Blood Diseases Institute  
Telephone: 513-636-1371 Fax: 513-636-3549  
E-mail: [stella.davies@cchmc.org](mailto:stella.davies@cchmc.org)
- **Roger Cornwall, MD**, Assistant Professor of Pediatrics, Division of Orthopaedics (Hand Surgery)  
Telephone: 513-636-7319 Fax: 513-636-3928  
E-mail: [roger.cornwall@cchmc.org](mailto:roger.cornwall@cchmc.org)

(Continued on the next page)

## BONE MARROW FAILURE, cont'd

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

- **Richard Harris, MD**, Professor of Pediatrics, Director of the Bone Marrow Failure Program, Division of Bone Marrow Transplantation and Immune Deficiency, Cancer and Blood Diseases Institute  
Telephone: 513-636-8610 Fax: 513-636-7951  
E-mail: [richard.harris@cchmc.org](mailto:richard.harris@cchmc.org)
- **Jill Huppert, MD, MPH**, Pediatric and Adolescent Gynecology  
Telephone: 513-636-2911 Fax: 513-636-8844  
E-mail: [jill.huppert@cchmc.org](mailto:jill.huppert@cchmc.org)
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E-mail: [parinda.mehta@cchmc.org](mailto:parinda.mehta@cchmc.org)
- **Kasiani Myers, MD**, Instructor of Clinical Pediatrics, Division of Bone Marrow Transplantation and Immune Deficiency, Cancer and Blood Diseases Institute  
Telephone: 513- 803-3218 Fax: 513-636-7951
- **Susan R. Rose, MD, MEd**, Professor of Pediatrics, Pediatric Endocrinology  
Telephone: 513-636-4744  
E-mail: [susan.rose@cchmc.org](mailto:susan.rose@cchmc.org)
- **Meilan Rutter, MD**, Associate Professor of Pediatrics, Division of Endocrinology  
Telephone: 513-636-4744  
E-mail: [meilan.rutter@cchmc.org](mailto:meilan.rutter@cchmc.org)
- **Michael Rutter, MD**, Associate Professor of Pediatrics, Division of Otolaryngology  
Telephone: 513-636-4881 Fax: 513-636-8133  
E-mail: [mike.rutter@cchmc.org](mailto:mike.rutter@cchmc.org)
- **Nada Yazigi, MD**, Assistant Professor of Pediatrics, Pediatric Gastroenterology  
Telephone: 513-636-4415 Fax: 513-636-7805  
E-mail: [nada.yazigi@cchmc.org](mailto:nada.yazigi@cchmc.org)

#### Services Offered:

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

## BONE MARROW FAILURE, cont'd

### City Of Hope

1500 E. Duarte Rd.

Duarte, CA 91010

Telephone: 626-301-8442

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

- **Joseph Rosenthal, MD**, Director, Pediatric Hematology/Hematopoietic Cell Transplantation
- **Debbie Hitt, RN**, Nurse-Coordinator, Pediatric Hematology/Hematopoietic Cell Transplantation
- **Nadia Ewing, MD**, Director, Pediatric Hematology
- **Anna Pawlowska, MD**, Pediatric Hematology/Hematopoietic Cell Transplantation
- **April Sorrell, MD**, Pediatric Hematology/Hematopoietic Cell Transplantation and Pediatric Clinical Cancer Genetics
- **Julie Wolfson, MD**, Pediatric Hematology/Hematopoietic Cell Transplantation
- **Joyce Collins, PhD**, Cytogenetics
- **Smita Bhatia, MD**, Pediatrics, Hematology/Hematopoietic Cell Transplantation and Director, Population Sciences
- **Christina Cabanillas, LCSW**, Social Worker, Pediatric Hematology/Hematopoietic Cell Transplantation

#### Services Offered:

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

### Dana-Farber Cancer Institute

44 Binney St.

Boston, MA 02115

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

#### Services Offered:

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

## BONE MARROW FAILURE, cont'd

### Fred Hutchinson Cancer Research Center

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

### Seattle Children's Hospital

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

- **Akiko Shimamura, MD, PhD**, Marrow Failure Program, Pediatric Hematology-Oncology, Seattle Children's Hospital, Associate Member, Fred Hutchinson Cancer Research Center Associate Professor of Pediatrics, University of Washington School of Medicine  
Telephone: 206-667-1127 Fax: 206-667-5255  
E-mail: [ashimamu@fhcrc.org](mailto:ashimamu@fhcrc.org)
- **Hans-Peter Kiem, MD**, Member, Fred Hutchinson Cancer Research Center, Investigator, Markey Molecular Medicine Center, Adjunct Associate Professor of Pathology, Associate Professor of Medicine, University of Washington School of Medicine  
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- **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  
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E-mail: [awoolfre@fhcrc.org](mailto:awoolfre@fhcrc.org)
- **Jennifer Adair, PhD**, Clinical Research Associate, Fred Hutchinson Cancer Research Center  
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Email: [jadair@fhcrc.org](mailto:jadair@fhcrc.org)
- **Pam Becker, MD, PhD**, Associate Professor of Medicine, University of Washington School of Medicine, Department of Hematology  
Telephone: 206-288-2294 Fax: 206-543-3560
- **Jean Sanders, MD**, Member, Fred Hutchinson Cancer Research Center, Professor of Pediatrics, University of Washington School of Medicine, Medical Director, Pediatric Hematopoietic Cell Transplant Program  
Telephone: 206-667-4348 Fax: 206-667-5899

#### Services Offered:

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

## BONE MARROW FAILURE, cont'd

### Hackensack University Medical Center

#### Tomorrow's Children Institute

30 Prospect Ave.

Hackensack, NJ 07601

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

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

#### Services Offered:

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

### Memorial Sloan-Kettering Cancer Center

1275 York Ave.

New York, NY 10021

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

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

#### Services Offered:

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

## BONE MARROW FAILURE, cont'd

### Mount Sinai School of Medicine

Novel Therapeutics and Stem Cell Transplantation Program  
Division of Hematology-Oncology  
Annenberg 24-42, Box 1079  
One Gustave L. Levy Pl.  
New York, NY 10029

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

#### Services Offered:

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

### National Cancer Institute

Clinical Genetics Branch, Division of Cancer Epidemiology and Genetics,  
National Institutes of Health  
6120 Executive Blvd., Executive Plaza South, Room 7020  
Rockville, MD 20892-7231  
[www.marrowsfailure.cancer.gov](http://www.marrowsfailure.cancer.gov)

- **Lisa Leathwood, RN, BSN**, Research Nurse and Study Coordinator  
Telephone: 301-212-5250 and 800-518-8474 Fax: 301-881-1463  
E-mail: [lisaleathwood@westat.com](mailto:lisaleathwood@westat.com)
- **Blanche P. Alter, MD, MPH, FAAP**  
Telephone: 301-402-9731 Fax: 301-496-1854  
E-mail: [alterb@mail.nih.gov](mailto:alterb@mail.nih.gov)
- **Neelam Giri, MD, FAAP**  
Telephone: 301-594-7642 Fax: 301-496-1854  
E-mail: [girin@mail.nih.gov](mailto:girin@mail.nih.gov)
- **Pamela Stratton, MD**, Chief, Gynecology Consult Service  
Telephone: 301-496-9079 Fax: 301-480-6703  
E-mail: [stratton@nih.gov](mailto:stratton@nih.gov)
- **Carter Van Waes, MD, PhD**, Chief Head and Neck Surgery Branch; Clinical Director, National Institute on Deafness and other Communication Disorders  
Telephone: 301-402-4216 Fax: 301-402-1140  
E-mail: [vanwaesc@nidcd.nih.gov](mailto:vanwaesc@nidcd.nih.gov)

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

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

#### **Services Offered:**

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

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

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

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

#### **Services Offered:**

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

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

#### **The Rockefeller University**

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

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

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## BONE MARROW FAILURE, cont'd

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

#### Services Offered:

#### Genetic Services on Research Protocol:

- ◆ International Fanconi Anemia Registry (IFAR);
- ◆ Derivation of lymphoblastoid cell line for complementation testing; maintenance of Fanconi anemia cell and DNA repositories;
- ◆ Mutation screening of probands for FA genes under investigation by the laboratory.

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

- **Farid Boulad, MD**  
Memorial Sloan-Kettering Cancer Center, New York, NY  
Telephone: 212-639-6684 Fax: 212-717-3555  
E-mail: *bouladf@mskcc.org*
- **Stella Davies, MBBS, PhD, MRCP**  
Cincinnati Children's Hospital Medical Center, Cincinnati, OH  
Telephone: 513-636-1371 Fax: 513-636-3459  
E-mail: *stella.davies@cchmc.org*
- **Margaret L. MacMillan, MD**  
University of Minnesota, Minneapolis, MN  
Telephone: 612-626-2778 Fax: 612-626-2815  
E-mail: *macmi002@umn.edu*

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

#### Bone Marrow Failure Program

Division of Hematology/Oncology and Stem Cell Transplantation  
269-01 76th Ave., Rm. 225  
New Hyde Park, New York 11040

- **Adrianna Vlachos, MD**, Assistant Professor of Pediatrics, Head, Bone Marrow Failure Program and Associate Head, Stem Cell Transplant Program  
Telephone: 718-470-3611 Fax: 718-343-2961  
E-mail: *avlachos@lij.edu*
- **Johnson M. Liu, MD**, Les Nelkin Professor of Pediatrics, Head, Section of Experimental Hematology and Les Nelkin Memorial Pediatric Oncology Research Laboratory  
Telephone: 718-470-7174  
E-mail: *jliu3@nshs.edu*
- **Jeffrey M. Lipton, MD, PhD**, Professor of Pediatrics, Chief, Division of Hematology/Oncology and Stem Cell Transplantation  
Telephone: 718-470-3460  
E-mail: *jlipton@lij.edu*

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## BONE MARROW FAILURE, cont'd

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

#### Services Offered:

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

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

Hematology Clinic

770 Welch Road, Suite 261

Palo Alto, CA 94304

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

Pediatric Hematology/Oncology Academic Office

1000 Welch Road, Suite 300

Palo Alto, CA 94304

#### Hematology/Oncology Telephone: 650-723-5535

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

#### Stem Cell Transplant Telephone: 650-725-9250

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

#### Services Offered:

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

## BONE MARROW FAILURE, cont'd

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

MMC 366, University of Minnesota

420 Delaware St., S.E.

Minneapolis, MN 55455

Telephone: 612-273-2800

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

- **John E. Wagner, MD**, Fanconi Anemia Comprehensive Care Program Leader, Director, Division of Hematology/Oncology and Blood and Marrow Transplantation, CCRF/Hageboeck Family Chair in Pediatric Oncology & Clinical Director, Stem Cell Institute  
Telephone: 612-626-2961 Fax: 612-626-4074  
E-mail: [wagne002@umn.edu](mailto:wagne002@umn.edu)
- **Margaret L. MacMillan, MD**, Fanconi Anemia Comprehensive Care Program Leader, Associate Professor, Department of Pediatrics, Division of Blood and Marrow Transplantation  
Telephone: 612-626-2778 Fax: 612-626-2815  
E-mail: [macmi002@umn.edu](mailto:macmi002@umn.edu)
- **Anna Petryk, MD**, Pediatric Endocrinology  
Telephone: 612-624-5409 Fax: 612-626-5262  
E-mail: [petry005@umn.edu](mailto:petry005@umn.edu)
- **Sarah Jane Schwarzenberg, MD**, Pediatric Gastroenterology  
Telephone: 612-624-1133 Fax: 612-626-0639  
E-mail: [schwa005@umn.edu](mailto:schwa005@umn.edu)
- **Daniel Mulrooney, MD, MS**, Stem Cell Transplantation/Late Effects Clinic  
Telephone: 612-626-2961 Fax: 612-626-1434  
E-Mail: [baker084@umn.edu](mailto:baker084@umn.edu)
- **Frank Ondrey, MD, PhD, FACS**, Otolaryngology  
Telephone: 612-624-5900  
E-mail: [ondre002@umn.edu](mailto:ondre002@umn.edu)
- **Rahel G. Ghebre, MD**, Gynecologic Oncology  
Telephone: 612-626-2613 Fax: 612-626-0665  
E-mail: [ghebr004@umn.edu](mailto:ghebr004@umn.edu)
- **Ann E. Van Heest, MD**, Dept. of Orthopaedic Surgery  
Telephone: 612-273-8086 Fax: 612-273-7959  
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)

(Continued on the next page)

## BONE MARROW FAILURE, cont'd

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

#### Services Offered:

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

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

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

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

**To Contact us:**

Telephone: 214-456-2382 or 214-456-6102  
Email: *BoneMarrowFailure@UTSouthwestern.edu*

**Nurse Coordinator:**

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

**Medical Staff:**

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

**Services Offered:**

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

# BONE MARROW DONOR REGISTRIES

## **DKMS Americas**

33 East 33rd Street, Suite 501

New York, NY 10016

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

Telephone: 1-866-340-DKMS (3567)

E-mail: [info@dkmsamericas.org](mailto:info@dkmsamericas.org)

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

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

- ◆ Organizes thousands of Bone Marrow Donor Drives across the U.S. to recruit healthy, committed donors; We do not make the testing fee mandatory, but rely on donations to support our life-saving work;
- ◆ Provides patients with access to more than 2 million registered donors; more than 25% of all transplants are provided by DKMS;
- ◆ Performs HLA- A\*, B\*, C\*, DR\* high-resolution typing on every registered donor, minimizing the search time for finding the best possible donor match for a patient;
- ◆ Coordinates all transports of bone marrow and blood stem cells from Germany to USA.

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

3001 Broadway Street NE, Suite 100

Minneapolis, MN 55413-1753

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

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

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

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

### **Services Offered:**

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

# CORD BLOOD REGISTRIES

## **Cord Blood Registry®**

Designated Transplant Program (DTP)

Cord Blood Registry

1200 Bayhill Drive, 3rd Floor

San Bruno, CA 94066

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

Telephone: 1-888-Cord-Blood

### **Services Offered:**

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

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

3001 Broadway St. NE, Suite 100

Minneapolis, MN 55413

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

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

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

### **Services Offered:**

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

## ENDOCRINOLOGY

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

3333 Burnet Ave.  
Cincinnati, OH 45229

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

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

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

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

## GASTROENTEROLOGY

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

3333 Burnet Ave.  
Cincinnati, OH 45229

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

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

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

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

## GENETIC COUNSELING

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

MMC 366, University of Minnesota

420 Delaware St., S.E.

Minneapolis, MN 55455

Telephone 612-273-2800

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

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

## GYNECOLOGY

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

3333 Burnet Ave.

Cincinnati, OH 45229

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

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

Bldg 10, CRC, Room 1-3140

10 Center Dr. MSC 1109

Bethesda, MD 20892-1109

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

## GYNECOLOGY, cont'd

### **Memorial Sloan-Kettering Cancer Center**

1275 York Ave.  
New York, NY 10021

- **Mercedes Castiel, MD**, Gynecology  
Telephone: 212-639-5060  
E-mail: [castielm@mskcc.org](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](mailto:vanhe003@umn.edu)
- **Gillette Children's Specialty Healthcare**  
200 University Avenue East  
St. Paul, MN 55101  
Telephone: 651-291-2848
- **Shriners Hospital for Children, Twin Cities Unit**  
2025 East River Parkway  
Minneapolis, MN 55414  
Telepone: 612-596-6100

#### **Services Offered:**

- ◆ Hand and upper extremity surgery in the pediatric population

## HAND SURGEONS, cont'd

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

3333 Burnet Ave.  
Cincinnati, OH 45229

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

### Shriners Hospital for Children

3551 North Broad St.  
Philadelphia, PA 19140

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

#### Services Offered:

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

## OPHTHALMOLOGY

### Boston Foundation for Sight

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

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

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

#### Services Offered:

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

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

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

3333 Burnet Ave.  
Cincinnati, OH 45229

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

## Johns Hopkins Medical Institutions

601 N. Caroline Street, 6th Floor  
Baltimore, MD 21287-0910

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

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

## Memorial Sloan-Kettering Cancer Center

1275 York Ave.  
New York, NY 10021

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

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

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

### National Institutes of Health

NIDCD/NIH

10 Center Drive, Building 10  
Bethesda, MD 20892

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

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

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

**Clinical Interests:** Associate investigator on Dr. Blanche Alter's protocol, for diagnosis of head and neck mucosal lesions and cancers for participating patients.

### University of Chicago Medical Center

5841 S. Maryland Avenue  
Chicago, IL 60634

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

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

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

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

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

### **University of Cincinnati, College of Medicine**

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

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

### **University of Minnesota, Fanconi Anemia Comprehensive Care Program**

### **University of Minnesota Medical Center and Amplatz Children's Hospital**

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

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

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

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

Suite 300  
203 Lothrop Street  
Pittsburgh, PA 15213

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

**Specialty:** Otolaryngology

**Sub Specialty:** Head & Neck Surgery

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

### University of Texas MD Anderson Cancer Center

1515 Holcombe Blvd., Unit 441  
Houston, TX 77030

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

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

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

## PRE-IMPLANTATION GENETIC DIAGNOSIS

### The Genesis Genetics Institute, Genomic Technology Center

Genomics Center at Samaritan - A1100  
5555 Conner  
Detroit, MI 48213  
[www.genesisgenetics.org](http://www.genesisgenetics.org)

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

#### **Services Offered:**

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

## PRE-IMPLANTATION GENETIC DIAGNOSIS, cont'd

### **The Reproductive Genetics Institute**

2825 N Halsted St.

Chicago, IL 60657

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

*www.reproductivegenetics.com*

E-mail: *rgiworld@gmail.com*

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

#### **Services Offered:**

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

## US Fanconi Anemia Testing Resources

Institution	Test	Cost	Covered by Insurance?	Approximate Time for Results
<b>Cincinnati Children's Research Foundation, Translational Trials Development Support Laboratory (TTDSL)</b> Cincinnati, OH •Stella Davies, MD 513-636-1371 <i>stella.davies@cchmc.org</i>	Complementation analysis for A, B, C, E, F, G, J, L (and FANCM analysis under development) in primary T-cells, lymphoblast cell lines (LCL, or fibroblasts) (Available to clinicians and researchers) <i>CLIA Certified*</i>	Varies	Varies	Varies, dependent upon gene
	FANCD2 western blot and monoubiquitination	Varies	Varies	Varies
	Mutation analysis (in collaboration with <b>The Rockefeller University</b> )	Varies	Varies	Varies
<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 <i>CLIA Certified*</i>	Varies (contact lab)	Generally	10 working days
	Complementation group (Research)	No charge	N/A	Minimum 3-6 months
	Mutation analysis (Research)	No charge	N/A	Minimum 3-6 months
	D2 western blot (Research)	No charge	N/A	1 week
<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 <i>CLIA Certified*</i>	Contact lab	Varies	1-2 weeks
	Complementation group (Research)	No charge	N/A	Unknown
	Mutation Analysis for A, C, G, E, F (Please see GeneTests for further information at <a href="http://geneclinics.org">geneclinics.org</a> ) <i>CLIA Certified*</i>	Contact lab	Contact insurance carrier	3-4 weeks

Institution	Test	Cost	Covered by Insurance?	Approximate Time for Results
<b>Quest Diagnostics</b> Chantilly, VA • Aimee Martin, MGC, CGC 800-336-3718, ext. 7148 <i>aimee.d.martin@questdiagnostics.com</i>	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> <i>CLIA Certified*</i>	Varies	Generally	10 days-3 weeks
	Prenatal diagnosis <i>CLIA Certified*</i>	Varies	Generally	2-3 weeks
<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 IVS4=4-> and 322delG <i>CLIA Certified*</i>	\$205	Generally	8 days
<b>The Rockefeller University</b> New York, NY • Arleen Auerbach, PhD 212-327-7533 <i>auerbac@rockefeller.edu</i> • Francis Lach, Research Specialist 212-327-8862 <i>lachf@rockefeller.edu</i>	Mutation analysis (Research)	No charge	N/A	Varies
	D2 western blot (Research)	No charge	N/A	Varies

\*CLIA Certified: Clinical Laboratories Improvement Amendments (USA)

Additional testing information for Fanconi anemia is available at:

<http://geneclinics.org>

Select "Gene Reviews," then "Search by Disease"



# International Fanconi Anemia Treatment Resource Guide

*Editors' Note and Disclaimer: The resources provided in this guide are not meant to be inclusive. The reader should not consider the resources listed here to be endorsements 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

Rua General Carneiro, 181 - 15<sup>o</sup> andar  
80001-970-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: 55-41-3360-1007 Fax 55-41-3360-1015  
E-mail: *carmem\_bonfim@terra.com.br*
- **Ricardo Pasquini, MD, PhD**  
Telephone: 55-41-3360-1007 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.

## 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, MRCPC**, 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, 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)

## DENMARK

### University Hospital of Aarhus at Skejby

Brendstrupgaardsvej 100  
DK-8200 Aarhus N  
DENMARK

- **Niels Clausen, MD**, Department of Pediatrics  
Telephone: 45-8949-6858  
E-mail: [niecla@rm.dk](mailto:niecla@rm.dk)

#### Services Offered:

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

## FRANCE

### 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)

(Continued on the next page)

## FRANCE, cont'd

### Hôpital Saint-Louis, cont'd

#### Services Offered:

- ◆ 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.

## GERMANY, cont'd

### 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)

#### 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*

- **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

### 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*

### 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)

### 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*
- **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*
- **Enrico Cappelli, PhD**, Hematology Laboratory, G. Gaslini Children's Institute  
Telephone: 39-010-5636-693 Fax: 39-010-5636-714  
E-mail: *enicocappelli@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, 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.

## MEXICO

### **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@servidor.unam.mx](mailto:clarag@servidor.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.

## 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](mailto: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*

### Physicians:

- **Thuan-Chong Quah, MBBS**  
E-mail: *paqtc@nus.edu.sg*
- **Allen Yeoh Eng-Juh, MBBS**  
E-mail: *paeyej@nus.edu.sg*
- **Poh-Lin Tan, MBBS**  
E-mail: *poh\_lin\_tan@nuhs.edu.sg*
- **Pei-Lin Koh, MBBS**  
E-mail: *pei\_lin\_koh@nuhs.edu.sg*

### International Patient Liaison Centre:

Telephone (24hr Helpline): (65) 67792777

E-mail: *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

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

## Johannesburg Hospital

Division of Haematology and Oncology

Dept. of Pediatrics

Private Bag X39

Johannesburg 2000

South Africa

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

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

### **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.

## **SPAIN**

### **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*

## SPAIN, cont'd

### Universitat Autònoma de Barcelona

Chromosome Fragility Service (UAB-CFS)

Department of Genetics and Microbiology

08193 Bellaterra (Cerdanyola del Valles)

Barcelona, Spain

Web: [www.uab.es/surralleslab](http://www.uab.es/surralleslab)

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;
- ◆ 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.

## 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)

## THE NETHERLANDS, cont'd

### 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)

### 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](mailto:jpp.gille@vumc.nl)
- **Resie Vervenne, PhD**  
E-mail: [r.vervenne@vumc.nl](mailto:r.vervenne@vumc.nl)
- **Aggie Nieuwint, MSc**  
Contact for chromosomal breakage testing.  
E-mail: [awm.nieuwint@vumc.nl](mailto: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](mailto:jc.dorsman@vumc.nl)
- **Hans Joenje, PhD**  
E-mail: [joenje@vumc.nl](mailto:joenje@vumc.nl)
- **Johan P. de Winter, PhD**  
E-mail: [j.dewinter@vumc.nl](mailto:j.dewinter@vumc.nl)

(Continued on the next page)

## THE NETHERLANDS, cont'd

### VU Medical Center Amsterdam, cont'd

#### 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.

## TURKEY

### Istanbul 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*

## 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*

## **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, MRCP, 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

St. James's University Hospital  
Fanconi Anaemia - Multidisciplinary Clinic  
Beckett Street  
Leeds LS9 7TF United Kingdom

- **Professor Sally E. Kinsey, MD**, Paediatric Haematologist  
Telephone: 0113-206-4986 Fax: 0113-247-0248  
E-mail: [sally.kinsey@leedsth.nhs.uk](mailto:sally.kinsey@leedsth.nhs.uk)
- **Ben Sykes**, Nurse Co-ordinator  
Telephone: 0113-206-4986 Fax: 0113-247-0248  
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

Institution	Test	Cost	Covered by Insurance?	Approximate Time for Results
<b>CIEMAT, Hematopoiesis and Gene Therapy Division</b> Madrid, Spain • Juan Bueren, PhD 34-91-346-6518 <i>juan.bueren@ciemat.es</i>	Complementation Group (Research)	Free for Spanish patients	N/A	1 month
<b>Heinrich Heine University Medical Center</b> Düsseldorf, Germany • Helmut Hanenberg, MD 49-211-811 ext. 6103 or 6568 Fax - 9436 <i>Hanenberg@uni-duesseldorf.de</i>	Complementation Group (Research) ◦ Use of retroviruses for A, B, C, D1, D2, E, F, G, I, J, L, M, N in primary T-cells, bone marrow or fibroblasts or in lymphoblast cell lines (LCL) ◦ FANCD2 Western Blotting ◦ Collaborative mutation testing and research with University of Würzburg	No charge	N/A	2-4 weeks
<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>	No charge	Generally	2-3 weeks
<b>Universitat Autònoma de Barcelona</b> Barcelona, Spain • Jordi Surrallés, PhD 34-935-811-830 <i>surralleslab.uab.cat</i> <i>safero.uab.cat</i>	DEB Diagnostic Testing (Research), Diagnosis of Mosaicism	€ 290 + VAT to non-Spanish hospitals; varies for Spanish hospitals	N/A	1 month
	Mutation Analysis (Research) for Spanish Gypsy Population	€ 290 + VAT to non-Spanish hospitals; varies for Spanish hospitals	N/A	1 week

Institution	Test	Cost	Covered by Insurance?	Approximate Time for Results
<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> )	€ 560	Varies	1-2 weeks
	FANCD2 Immunoblots	€ 100	Yes	2 weeks
	Prenatal Diagnosis	Varies	Varies	Varies
	Mutation Analysis ( <i>Certified under Governmental and Societies</i> )	Varies with extent of sequencing	Yes	Varies; dependent upon gene
	Complementation Group	Complimentary when followed by mutation analysis	No	Varies
<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> )	€ 1100	Generally	3 months
	Mutation Analysis FANCC, -E, -F, and -G ( <i>Clinically Certified</i> )	€ 1100	Generally	3 months
	Mutation Analysis of other FANC genes ( <i>Clinically Certified</i> )	Varies	Generally	Varies
	Prenatal DNA diagnosis ( <i>Clinically Certified</i> )	Varies	Generally	1-2 weeks

Additional testing information for Fanconi anemia is available at:  
<http://geneclinics.org>  
 Select "Gene Reviews," then "Search by Disease"



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