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. Families are encouraged to ask clinicians about their experience treating patients with Fanconi anemia.

AUSTRALIA

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

- **Dr. Julie Curtin, MD, PhD**, Head Haematology Department
  Telephone: 612-9845-0000 Fax 612-9845-3332
  Email: juliee@chw.edu.au

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

- **Ida O’Brien**, Clinical Nurse Consultant BMT Follow Up
  Telephone: 612-9845-0000 Fax: 612-9845-2171
  Email: Idao1@chw.edu.au

- **A/Prof. Meredith Wilson**, Clinical Geneticist
  Telephone: 612-9845-3273 Fax: 612-9845-3204
  Email: merediw@chw.edu.au

- **A/Prof. David Little**, Director Orthopaedic Research
  Telephone: 612-9845-3352 Fax: 612-9845-3180
  Email: DavidL3@chw.edu.au

- **Professor Chris Cowell**, Head Endocrinology Department
  Telephone: 612-9845-0000 Fax: 612-9845-3170
  Email: chrisc@chw.edu.au

- **Dr. Carsten E. Palme, FRACS**, Surgeon, Otolaryngology Head & Neck Surgery
  Telephone: 612-9845-6025 Fax: 612-9845-7440
  Department of Surgery, Westmead Hospital
  Email: Carsten_Palme@wsahs.nsw.gov.au

- **Mark Schifter**, Oral Medicine and Oral Pathology
  Telephone: 612-9845-8716 Fax: 612-9845-5740
  Email: 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 anemia. 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;
- 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 Deck 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

- **Catherine Cole, MB BS, FRACP, FRCPA**, Clinical Director of Bone Marrow Transplantation Program
- **Tina Carter, FRACP, PhD**, Bone Marrow Transplant Physician
  Telephone: 08-9340-8222
  Email: Tina.Carter@health.wa.gov.au
Sydney Children’s Hospital
Cord & Marrow Transplant Program
Centre for Children’s Cancer & Blood Disorders
Sydney Children’s Hospital
High St, Randwick
Sydney, NSW, 2031
Australia

- **Dr. Tracey O’Brien**, Director, Cord & Marrow Transplant Program, Centre for Children’s Cancer and Blood Disorders
  Telephone: 02-93821733 Fax: 02-93821789
  Email: Tracey.OBrien@sesiahs.health.nsw.gov.au

- **Dr. Susan Russell**, Head Haematology, Centre for Children’s Cancer and Blood Disorders
  Telephone: 02-93821733 Fax: 02-93821789
  Email: Susan.Russell@sesiahs.health.nsw.gov.au

- **A/Prof. Richard Cohn**, Head, Oncology, Centre for Children’s Cancer and Blood Disorders
  Telephone: 02-93821731 Fax: 02-93821789
  Email: Richard.Cohn@sesiahs.health.nsw.gov.au

- **Anne Senner**, BMT Co-ordinator, Cord & Marrow Transplant Program, Centre for Children’s Cancer and Blood Disorders
  Telephone: 02-93821733 Fax: 02-93821789
  Email: Anne.Senner@sesiahs.health.nsw.gov.au

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

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

**AUSTRIA**

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

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

**Services Offered:**
Stem cell transplants for FA patients.

**BRAZIL**

Hospital de Clinicas, University of Parana
Servico 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
  Email: carmembonfim@gmail.com

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

**Services Offered:**
- Comprehensive clinic for FA patients;
- Out-patient unit for diagnostic procedures and treatment;
- Cytogenetics laboratory performing DEB chromosomal breakage testing and conventional cytogenetics of bone marrow;
- Transplant unit performing related and unrelated bone marrow and umbilical cord transplants.
- 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
  Email: yigal.dror@sickkids.ca

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

**Princess Margaret Hospital**

Ontario Cancer Institute
University of Toronto
610 University Ave
Toronto, Ontario, M5G 2M9, Canada

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

**University of Manitoba**

ON2021a-675 McDermot Ave.
Winnipeg, Manitoba, Canada R3E 0V9

- John J. Doyle, MD, FRCP, FAAP, Associate Professor, Dept. of Pediatrics and Child Health, University of Manitoba; Head, Pediatric Hematology/Oncology/BMT
  Telephone: (204) 787-4135  Fax: (204) 786-0195
  Email: john.doyle@cancercare.mb.ca and jdoyle2@hse.mb.ca

**COLOMBIA**

**Clinica Las Americas**

Diagonal 75 B #2 A80 Ofic. 520
Medellín
Antioquia, Colombia

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

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

Services offered:
Evaluation, medical treatment, FA stem cell transplantation.

**Dr. Adriana Linares**

Telephone: (571) 343-6600 (extension 1364, 1362, or 1280)
Email: alinaresb@gmail.com

- Clinica Colsubsidio
  Carrera 24 # 63 - 50
  Bogotá, Colombia

- National University of Colombia
  Carrera 45 No 26-85
  Building Uriel Gutierrez
  Bogotá, Colombia

Services Offered:
Pediatric hematology oncology, clinical evaluation, medical treatment and therapy.

**HematoOncologos S.A.**

Calle 5B 5 #38-10
Cali, Valle
Colombia

- Oscar Ramirez W, MD MPhil
  Telephone:+57-2-5561588 or mobile 317-4315011
  Email: oramirez1167@gmail.com or hopediatría@hematooncologos.com

Services Offered:
Pediatric hematology oncology, Hematopathology, clinical evaluation, medical therapy, stem cell transplantation related and unrelated.

**China**

**Mingfeng Zhao, MD, PhD**

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

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

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

Services Offered:
Stem cell transplants for FA patients.

DENMARK

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

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

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

FRANCE

Hôpital Robert 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
  Email: thierry.leblanc@rdb.aphp.fr

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

Services Offered (primarily for children):
- Bone marrow, peripheral stem cell and cord blood transplants;
- FA diagnosis: breakage tests, cell cycle, FancD2 analysis, mosaicism on skin biopsy, retroviral group complementation, bone marrow karyotype (Dr. Jean Soulier);
- Gene sequencing on grouped patients, in collaboration with Institut Curie (Pr. Dominique Stoppa-Lyonnet);
- Head and neck cancer evaluation and treatment (Dr. Francis Pascal and Dr. Arnaud Rigolet);
- Cell therapy laboratory (Dr. Jerome Larghero);
- Gene therapy laboratory (Dr. Philippe Leboulch).

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

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

- **Thierry Leblanc, MD**, Department of Pediatric Hematology
  Telephone direct: 33-1-4249-9725
  Secretary: 33-1-4249-9721 Fax: 33-1-4249-9823
  Email: thierry.leblanc@rdb.aphp.fr

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

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

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

Charité, Campus Virchow Klinikum, University Medicine, Berlin
Children’s Hospital
Augustenburger Platz 1
13353, Berlin, Germany

- Wolfram H. Ebell, MD
  Telephone: 49-30-450-566-014
  Fax: 49-30-450-566-919
  Email: 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
  Email: velleuer@uni-duesseldorf.de

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

Services Offered:
- 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
  Email: Rupert.Handgretinger@med.uni-tuebingen.de

Services Offered:
- Evaluation of new patients;
- Hematopoietic Stem Cell Transplantation from HLA-matched siblings, matched unrelated donors and haploidentical family donors;
- Co-transplantation of bone marrow with mesenchymal stem cells (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
  Email: vbaburao@hotmail.com

Services Offered:
□ Chromosomal breakage study using MMC and DEB test;
□ Cytogenic study from bone marrow and FISH analysis;
□ FANCD2 western blot.

Sahyadri Hospital
Pune’s Sahyadri Hospital (Deccan Gymkhana branch)
30C, Erandawane, Karve Road
Pune – 411 004, Maharashtra
India

• Dr. Shashikant Apte
  Telephone: +67213000 or +25403040
  Email: shashikant.apte@gmail.com

IRAN

Hematology-Oncology and SCT Research Center
Tehran University of Medical Sciences
Shariati Hospital
Kargar Ave.
14114, Tehran, Iran
http://horses.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
  Email: ghavamza@sina.tums.ac.ir

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

Services Offered:
□ Pediatric and Adult FA patients can be seen by specialists in pediatric and adult medicine;
□ Pediatrics Stem Cell Transplantation, 11-bed ward;
□ Adults Stem Cell Transplantation, 25-bed ward;
□ Stem cell laboratory;
□ Cord Blood Bank;
□ Cytogenic 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
  Email: slavin@CTCIcenter.com

Services Offered:
Allogeneic stem cell transplantation using well tolerated reduced intensity conditioning towards minimizing the risk of the transplant procedure by using nonmyeloablative stem cell transplantation (NST). Stem cell transplantation can also be considered from half-matched (haploidentically mismatched) family member while avoiding the risk of graft-versus-host disease.

Hannah Tamary, MD
Schneider Children’s Medical Center of Israel
14 Kaplan Street
PO Box 559
Petach Tikvah 49202
Israel
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 Email: 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 Email: 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 Email: 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, IRCCS Burlo Garofolo, University of Trieste Italy, for molecular diagnosis of FA;
- Haematopoiesis Laboratory (cell cultures, cytokine hypersensitivity tests);
- Cytogenetic Laboratory;
- Collaboration with European Centres of the EBMT (European Society for Blood and Marrow Transplantation) for data collection and retrospective studies.
- Close scientific collaboration with Dr. Grover Bagby (OHSU, OR, USA) on pathogenetic mechanism of marrow failure in FA;
- Comprehensive care and long-term follow-up of new and previously diagnosed patients, including: hematopoietic stem cell transplantation with related, unrelated, matched or mismatched donors (Dr. Edoardo Lanino, HSC Unit, G. Gaslini Children’s Hospital), head and neck cancer evaluation, endocrinology, orthopedic and nephrology clinic, psychological support;
- Ante-natal diagnosis available for patients in whom mutations are known;
- Experimental protocol for treatment of FA patients with bone marrow failure and no HSC donor available, using Etanercept (Anti TNF-alpha); Eudract Code (Italian Ministry of Health Registration Code) 2005-003096-20. This study has now been published.

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 Email: 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: 81-463-93-9567 Email: yabeh@is.icc.u-tokai.ac.jp
- Miharu Yabe, MD, Stem Cell Transplantation
  Telephone: 81-463-93-1121 Fax: 81-463-93-8607 Email: miharu@is.icc.u-tokai.ac.jp
- Shunichi Kato, MD, Stem Cell Transplantation
  Telephone: 81-463-93-1121 Fax: 81-463-91-6235 Email: 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.
KENYA

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

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

Services Offered:
- Diagnosis and management of all patients with FA including counselling of families
- Coordination of consultations with other subspecialities for management of FA related disorders

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
  Email: 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
  Email: imontero99@yahoo.com

- Dr. Ana Lilia Hernández Moreno

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

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

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

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

UMC Utrecht
Kinderarts - Hematoloog
Wilhelmina Kinderziekenhuis
Postbus 85090
3508 AB Utrecht
Huispostnr KC 03.063.0, 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
  Email: 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
  Email: jjp.gille@vumc.nl
• Resie Vervenne, PhD
  Email: r.vervenne@vumc.nl
• Aggie Nieuwint, MSc
  Contact for chromosomal breakage testing.
  Email: awm.nieuwint@vumc.nl

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

Contact:
Josephine C. Dorsman, PhD
Email: jc.dorsman@vumc.nl
• Hans Joenje, PhD
  Email: joenje@vumc.nl
• Johan P. de Winter, PhD
  Email: 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
  Email: Siobhan.Cross@cdhb.govt.nz

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

Starship Children’s Hospital
Grafton
Auckland 1023
New Zealand

• Dr. Nyree Cole
  Telephone: + 64 9 307 4919
  Email: Nyreec@adhb.govt.nz

SAUDI ARABIA

King Faisal Specialist Hospital & Research Center
Riyadh, Saudi Arabia

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

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

SOUTH AFRICA

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

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

Johannesburg Hospital
Division of Haematology and Oncology
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

SINGAPORE

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

• Poh-Lin Tan, MBBS, MMED (Paediatrics)
  Email: poh_lin_tan@nuhs.edu.sg

International Patient Liaison Centre:
Telephone (24hr Helpline): (65) 67792777
Email: iplc@nhg.com.sg

Services Offered:
☐ FACT accredited Paediatric Blood and Marrow Transplant Program (FACT accreditation in September 2012);
☐ Paediatric Sub-specialties: Adolescent Medicine, Allergy, Cardiology, Developmental Paediatrics, Endocrinology, Gastroenterology, Genetics, Haematology, Infectious Diseases, Intensive Care, Nephrology, Neurology, Oncology, Otolaryngology, Psychiatry, Pulmonology, Rheumatology, Surgery.

(Continued on next page)
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
  Mobile:+27-82-809-5797  Fax: 27-11-489-9226
  Email: amanda.krause@nhls.ac.za

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

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
  Email: cjaconko@mweb.co.za

Services Offered:
□ Diagnosis and management of FA patients and their families of all age groups;
□ Coaching and counseling families towards a healthy and optimum lifestyle with FA;
□ Coordination of consultations with other subspecialties for management of FA-related disorders.

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
  Mobile Phone: 083-444-7233  Fax: 27-51-4443230
  Email: StonesDK@UFS.ac.za

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

SPAIN

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

• Dr. Cristina Belendez
  Telephone: 91-529-00-37
  Email: cbelendez.hgugm@salud.madrid.org

Hospital Universitario de la Princesa
C/Doctor Esquerdo, 45
28028 Madrid, Spain

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

Hospital Vall d’Hebrón
Pediatric Oncology
Pg Vall D’Hebrón 119-129
Barcelona 08035, Spain

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

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

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

• Dra. Marta Prudencio, Department of Hematology and Oncology
  Telephone: 91-503-5938 Fax: 91-503-5960
CIEMAT/CIBERER
Hematopoiesis and Gene Therapy Division, CIEMAT/CIBER of Rare Diseases (CIBERER)
Madrid, Spain
www.ciemat.es
Spanish Fanconi Anemia Network: www.redfanconi.org

- **Juan Bueren, PhD**, Head of Hematopoiesis and Gene Therapy
  Telephone: 34-91-346-6518
  Email: juan.bueren@ciemat.es

- **José A. Casado**, Senior Researcher
  Telephone: 34-91-496-2525
  Email: jose.casado@ciemat.es

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

- **Laura Pérez**, Technical Assistance
  Telephone: 34-91-496-2523
  Email: laura.perez@ciemat.es

- **Mª Luz Lozano**, Technical Assistance
  Telephone: 34-91-346-6255
  Email: luz.lozano@ciemat.es

- **Paula Río**, Senior Researcher
  Telephone: 34-91-346-0890
  Email: paula.rio@ciemat.es

- **Susana Navarro**, Senior Researcher
  Telephone: 34-91-346-0891
  Email: s.navarro@ciemat.es

Services Offered:
- Coordination of the FA Spanish registry;
- FA subtyping by retrovirus mediated gene transfer;
- Analysis of the hematopoietic reserve in bone marrow samples from FA patients (CD34+ cells and Colony Forming Cells).

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

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

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

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

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

TURKEY

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

- **Nevin Yalman, MD**, President, Fanconi Anemia Association, Professor, Pediatric Hematologist
  Telephone: 9-212-414-20-00, x 31208
  Fax: 9-212-635-11-68
  Email: nevinyalman@gmail.com
Birmingham Children’s Hospital
Steelhouse Lane
Birmingham, West Midlands B4 6NH United Kingdom
• Phil Darbyshire, MD, Consultant Pediatric Hematologist
  Telephone: 44-121-333-9999
  Email: Phil.Darbyshire@bch.nhs.uk

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
  Email: colin.steward@uhbristol.nhs.uk

Services Offered:
- Comprehensive diagnostic and routine hematological 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
  Email: Josu.delaFuente@imperial.nhs.uk

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
  Email: sally.kinsey@leedsth.nhs.uk
• Ben Sykes, Nurse Co-ordinator
  Telephone: 0113-392-7379 Fax: 0113-392-6629
  Email: 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.