Journal of the American College of Cardiology © 2001 by the American College of Cardiology Published by Elsevier Science Inc. Vol. 37, No. 5, 2001 ISSN 0735-1097/01/\$20.00 PII S0735-1097(01)01272-4

BETHESDA CONFERENCE REPORT

32nd Bethesda Conference: "Care of the Adult With Congenital Heart Disease"*

Gary D. Webb, MD, FACC, Conference Co-Chair Roberta G. Williams, MD, FACC, Conference Co-Chair

This Conference, sponsored by the American College of Cardiology, was held at Heart House, Bethesda, Maryland, October 2–3, 2000.

Participants

HUGH D. ALLEN, MD, FACC

Chief, Pediatric Cardiology Physician-in-Chief Columbus Children's Hospital 700 Children's Drive Room ED622 Columbus, OH 43205-2696

JOSEPH S. ALPERT, MD, FACC

Professor of Medicine Head of Department of Medicine University of Arizona Health Sciences Center 1501 N. Campbell Avenue Tucson, AZ 85724-5035

JACQUES I. BENISTY, MD, FACC

Boston Adult Congenital Heart Service Department of Cardiology Children's Hospital 300 Longwood Avenue Boston, MA 02115-5737

YVONNE BERNARD, RN

Case Manager Division of Pediatric Cardiology Vanderbilt University Medical Center D2220 Medical Center North Nashville, TN 37232-2572

ALAN C. BRAVERMAN, MD, FACC

Associate Professor of Medicine One Barnes-Jewish Hospital Plaza Suite 16419 East Pavilion St. Louis, MO 63110 National Marfan Foundation

JOSEPH R. CARVER, MD, FACC Senior Medical Director

Senior Medical Director Aetna U.S. Healthcare 980 Jolly Road Mail Stop U21A Blue Bell, PA 19422

MELVIN D. CHEITLIN, MD, MACC

Emeritus Professor of Medicine University of California at San Francisco San Francisco General Hospital, Room 5G1 1001 Potrero Avenue San Francisco, CA 94110

JOHN S. CHILD, MD, FACC

Professor of Medicine UCLA School of Medicine Division of Cardiology Department of Medicine Los Angeles, CA 90024

RUTH L. COLLINS-NAKAI, MD, FACC

President, Canadian Cardiovascular Society 15239 43rd Avenue Edmonton, Alberta T6G 5R3 CANADA

GORDON K. DANIELSON, MD, FACC

Roberts Professor of Surgery Mayo Medical Center 200 First Street, SW Rochester, MN 55905-0001

WILLIAM R. DAVIDSON, JR., MD, FACC

Director, Program for Adults with CHD Director, Echocardiography Cardiology H047 M.S. Hershey Medical Center 500 University Drive Hershey, PA 17033

JOHN E. DEANFIELD, MD, FACC

Professor of Cardiology Cardiothoracic Unit Great Ormond Street Hospital Institute of Child Health Great Ormond Street London, WC1N 3JH UNITED KINGDOM

RICHARD M. DONNER, MD

Staff Pediatric Cardiologist The Children's Hospital of Philadelphia Division of Cardiology 34th and Civic Center Blvd Philadelphia, PA 19104-4399

ANNIE DORE, MD, FRCP

Assistant Professor of Medicine Montreal Heart Institute 5000 Belanger Est Montreal, Quebec H1T 1C8 CANADA

DAVID J. DRISCOLL, MD, FACC

Professor of Pediatrics Head, Section of Pediatric Cardiology Mayo Clinic 200 First Street, S.W. Rochester, MN 55905-0001

JOSEPH P. DROZDA, JR., MD, FACC

Principal, Carevergence Associate Director, Unity Health Research 36 Picardy Hill Drive Chesterfield, MO 63017-7127

SUSAN M. FERNANDES, MHP, PA-C

Boston Adult Congenital Heart Service Department of Cardiology Children's Hospital 300 Longwood Avenue Boston, MA 02115-5737

^{*}The recommendations set forth in this report are those of the Conference participants and do not necessarily reflect the official position of the American College of Cardiology.

When citing this document, the American College of Cardiology would appreciate the following citation format: Care of the Adult With Congenital Heart Disease. Presented at the 32nd Bethesda Conference, Bethesda, Maryland, October 2–3, 2000. J Am Coll Cardiol 2001;37:1161–98.

This document is available on the American College of Cardiology Web site at www.acc.org. Reprints of this document are available for \$5.00 each by calling 800-253-4636 (U.S. only) or by writing the Resource Center, American College of Cardiology, 9111 Old Georgetown Road, Bethesda, Maryland 20814.

ELYSE FOSTER, MD, FACC

Associate Professor of Clinical Medicine University of California, San Francisco Box 0214, Rm. 314A Moffitt Hospital 505 Parnassus Avenue, M314A San Francisco, CA 94143-0214

JAMES M. FOX, MS, MD

Cardiology Fellow Division of Cardiology University of Iowa Hospital 200 Hawkins Drive Room E318-5 Iowa City, IA 52242

MICHAEL D. FREED, MD, FACC

Senior Associate Department of Cardiology Children's Hospital 300 Longwood Avenue Boston, MA 02115-5737

VALENTIN FUSTER, MD, PhD, FACC

Director
Zena & Michael A. Wiener Cardiovascular
Institute
Mount Sinai Medical Center
One Gustave Levy Place
Box 1030
New York, NY 10029-6500

ARTHUR GARSON, JR., MD, MPH, MACC

Senior Vice President
Dean for Academic Operations
Texas Children's Hospital
Baylor College of Medicine
6621 Fannin Street
MC1-4460
Houston, TX 77030

THOMAS P. GRAHAM, Jr., MD, FACC

Director, Pediatric Cardiology Vanderbilt Medical Center 1161 21st Avenue, South (D2220 MCN) Nashville, TN 37232-0001

LOUISE HARRIS, MD, CHB, FACC

Associate Professor of Medicine & Consultant Electrophysiologist University of Toronto Congenital Cardiac Centre for Adults Toronto General Hospital 150 Gerrard Street West Gerrard Wing 3-562 Toronto, Ontario M5G 2C4 CANADA

JULIEN I. E. HOFFMAN, MD, FACC

Professor of Pediatrics (Emeritus)
Room M 1331, Box 0544
University of California
505 Parnassus Avenue
San Francisco, CA 94143-0001

CHARLES E. IRWIN, JR., MD

Professor of Pediatrics Vice Chair, Department of Pediatrics Director, Division of Adolescent Medicine University of California, San Francisco 3333 California Street, Suite 245 Box 0503, LH 245 San Francisco, CA 94143-0503

JOHN A. JARCHO, MD, FACC

Medical Co-Director, Cardiac Transplant Program Brigham & Women's Hospital Cardiovascular Division 75 Francis Street Boston, MA 02115

SAMUEL KAPLAN, MD, FACC

Professor of Pediatrics University of California at Los Angeles Heart Center, Suite 330 200 UCLA Medical Plaza Los Angeles, CA 90095-6946

RAE-ELLEN W. KAVEY, MD, FACC

SUNY Health Science Center at Syracuse Division of Pediatric Cardiology 725 Irving Avenue, Room 804 Syracuse, NY 13210 American Heart Association

HARLAN M. KRUMHOLZ, MD, FACC

Associate Professor of Medicine & Epidemiology and Public Health Yale University School of Medicine 333 Cedar Street Room IE-61 SHM New Haven, CT 06520

$\hbox{MICHAEL J. LANDZBERG, MD, FACC}$

Director, Boston Adult Congenital Heart Group Department of Cardiology Children's Hospital & Brigham & Women's Hospital 300 Longwood Avenue Boston, MA 02115-5737

JAMES LANGILL

66 Waverly Road Woburn, MA 01801

RICHARD R. LIBERTHSON, MD

8 Hawthorne Place Suite 110 Boston, MA 02114

ARIANE MARELLI, MD, FRCP(c), FACC

Assistant Professor of Medicine
McGill University
McGill University Health Care Center
1650 Cedar Avenue
Division of Cardiology E-500
Montreal, Quebec H3G 1A4
CANADA

JOHN E. MAYER, JR., MD, FACC

Professor of Surgery Harvard Medical School Sr. Associate in Cardiac Surgery Children's Hospital Cardiovascular Surgery 300 Longwood Avenue Boston, MA 02115-5737

FRANK X. McGOWAN, Jr., MD

Associate Professor of Anesthesiology (Pediatrics) Co-Director, Cardiac Anesthesia Services Cardiac Anesthesia Service Children's Hospital 300 Longwood Avenue Boston, MA 02115-5737

PETER McLAUGHLIN, MD, FACC

Professor of Medicine
University of Toronto Congenital Cardiac
Centre for Adults
University Health Network
Toronto General Hospital
200 Elizabeth Street
Eaton North, 12-224
Toronto, Ontario M5G 2C4
CANADA

ROGER B. B. MEE, MD, CHB

Chairman, Pediatric and Congenital Heart Surgery The Cleveland Clinic Foundation 9500 Euclid Avenue, M-41 Cleveland, OH 44195-0001

PAMELA D. MINER, RN, MN, NP

Nurse Practitioner Ahmanson/UCLA Adult Congenital Heart Disease Center 10833 LeConte Avenue Room 47-123 CHS Los Angeles, CA 90095

DOUGLAS S. MOODIE, MD, FACC

Chairman, Division of Pediatrics The Cleveland Clinic Foundation 9500 Euclid Ave., A120 Cleveland, OH 44195-0001

JOHN W. MOORE, MD, MPH, FACC

The Heart Center for Children St. Christopher's Hospital for Children Erie Avenue at Front Street Philadelphia, PA 19134 American Academy of Pediatrics

DANIEL J. MURPHY, JR., MD, FACC

The Cleveland Clinic Foundation 9500 Euclid Avenue, M-41 Cleveland, OH 44195-0001 International Society for Adult Congenital Cardiac

1164 Webb and Williams 32nd Bethesda Conference Participants

SUZANNE R. PATTEE, JD

Vice President of Public Policy & Patient Affairs Cystic Fibrosis Foundation 6931 Arlington Road, #200 Bethesda, MD 20814 Cystic Fibrosis Foundation

GAIL D. PEARSON, MD, ScD, FACC

Leader, Heart Development, Function & Failure Scientific Research Group Heart Research Program
National Heart, Lung & Blood Institute
National Institutes of Health
6701 Rockledge Drive
Room 9200, MSC 7940
Bethesda, MD 20892-7940
National Heart, Lung & Blood Institute

JOSEPH K. PERLOFF, MD, FACC

Director, Ahmanson/UCLA Adult Congenital Heart Disease Center Professor of Medicine and Pediatrics University of California at Los Angeles Division of Cardiology Room 47-123 CHS 10833 LeConte Avenue Los Angeles, CA 90095-1679

REED E. PYERITZ, MD, PHD

Chair, Department of Human Genetics Professor of Human Genetics, Medicine & Pediatrics MCP Hahnemann School of Medicine 320 E North Avenue Pittsburgh, PA 15212-4772

GRAHAM J. REID, PhD, C PSYCH

Assistant Professor, Psychology and Family Medicine University of Western Ontario Asst. Professor, Public Health Sciences & Medicine University of Toronto SSC 7310 London, Ontario N6A 5C2 CANADA

JOHN G. REISS, PhD

Director, Policy and Program Affairs Associate Professor of Pediatrics University of Florida 5700 SW 34th Street, Suite 323 Gainesville, FL 32608 Institute for Child Health Policy

SARA ROSENBAUM, JD

Hirsh Professor, Health Law & Policy George Washington University Medical Center School of Public Health and Health Services 2021 K Street, NW Suite 800 Washington, DC 20006

ISOBEL A. RUSSELL, MD, PHD

Dept. of Anesthesia & Perioperative Care University of California at San Francisco 521 Parnassus Avenue San Francisco, CA 94143-0648

DAVID J. SAHN, MD, FACC

Professor and Director, Clinical Care Center for Congenital Heart Disease Pediatric Cardiology Oregon Health Sciences University 3181 SW Sam Jackson Park Road Portland, OR 97201-3098

MATHEW SERMER, MD

Chief of Obstetrics Toronto General Hospital 200 Elizabeth Street Toronto, Ontario M5G 2C4 CANADA

SAMUEL C. SIU, MD, SM, FACC

Director of Research
University of Toronto Congenital Cardiac
Centre for Adults
Division of Cardiology, PMCC 3-526
200 Elizabeth Street
Toronto, Ontario M5G 2C4
CANADA

DAVID J. SKORTON, MD, FACC

Vice President for Research The University of Iowa 201 Gilmore Hall Iowa City, IA 52242-1320

LAURENCE J. SLOSS, MD

Co-Director
Boston Adult Congenital Heart Service
Department of Cardiology
Children's Hospital
Department of Cardiology
300 Longwood Avenue
Boston, MA 02115-5737

JANE SOMERVILLE, MD, FACC

Professor Royal Brompton Hospital 81/83 Harley Street London, W1N 1DE UNITED KINGDOM

DAVID M. STRASSER, MD, FACC

Medicor Associates, Inc. 104 E. 2nd Street Erie, PA 16507

JON B. TINGELSTAD, MD, FACC

American Board of Pediatrics 111 Silver Cedar Court Chapel Hill, NC 27514 American Board of Pediatrics

SUSIE C. TRUESDELL, PA, MBA

Xerox Corporation 80 Linden Oaks Parkway Mail Stop 0804-02A Rochester, NY 14625

KAREN UZARK, PhD, PNP

Director of Cardiology Process and Improvement and Clinical Outcomes Children's Hospital Medical Center Cardiology Department 3333 Burnet Avenue, OSB-4 Cincinnati, OH 45229-3039

GEORGE F. VAN HARE, MD, FACC

Associate Professor of Pediatrics Stanford University 750 Welch Road, Suite 305 Palo Alto, CA 94304

ROBERT A. VOGEL, MD, FACC

Herbert Berger Professor of Medicine Head, Division of Cardiology University of Maryland Hospital 22 S. Greene Street, Rm. S3B06 Baltimore, MD 21201-1544

CAROLE A. WARNES, MD, FACC

Professor of Medicine Mayo Clinic Cardiovascular Diseases Rochester, MN 55905

GARY D. WEBB, MD, FACC

Director
University of Toronto Congenital Cardiac
Centre for Adults
Toronto General Hospital
200 Elizabeth Street
12EN 215
Toronto, Ontario M5G 2C4
CANADA
President—Canadian Adult Congenital Heart
Network
Conference Co-Chair

ROBERTA G. WILLIAMS, MD, FACC

Chairman, Department of Pediatrics
KECK School of Medicine
University of Southern California
Vice President for Pediatrics and Academic
Affairs
Childrens Hospital Los Angeles
4650 Sunset Blvd., MS 71
Los Angeles, CA 90027
Conference Co-Chair

Conference Steering Committee

GARY D. WEBB, MD, FACC, CONFERENCE CO-CHAIR
ROBERTA G. WILLIAMS, MD, FACC, CONFERENCE CO-CHAIR
JOSEPH S. ALPERT, MD, FACC
JOHN S. CHILD, MD, FACC
RUTH L. COLLINS-NAKAI, MD, FACC
ELYSE FOSTER, MD, FACC
ARTHUR GARSON, JR., MD, MPH, MACC
THOMAS P. GRAHAM, JR., MD, FACC
MICHAEL J. LANDZBERG, MD, FACC
RICHARD LIBERTHSON, MD
DANIEL J. MURPHY, JR., MD, FACC
DAVID J. SKORTON, MD, FACC
CAROLE A. WARNES, MD, FACC

Staff

American College of Cardiology

CHRISTINE W. McENTEE, EXECUTIVE VICE PRESIDENT
MARIE E. MICHNICH, DRPH., SENIOR ASSOCIATE EXECUTIVE VICE PRESIDENT
CHARLENE L. MAY, DIRECTOR, DOCUMENT DEVELOPMENT AND PRACTICE GUIDELINES
LISA B. BRADFIELD, MANAGER, DOCUMENT DEVELOPMENT