Cardiology in the Young

December 2016 HeartWeek Issue of Cardiology in the Young

HeartWeek 2016:

Johns Hopkins All Children's Hospital Andrews/Daicoff Cardiovascular Program 2016 Summit: Postgraduate Education in Pediatric and Congenital Cardiac Care Renaissance Vinoy Resort & Golf Club, Saint Petersburg, Florida Thursday, February 11, 2016 and Friday, February 12, 2016 and

Johns Hopkins All Children's Hospital 16th International Symposium on Congenital Heart Disease Special Focus: Pediatric and Congenital Diseases of the Aorta Co-Sponsor: The American Association for Thoracic Surgery (AATS) Renaissance Vinoy Resort & Golf Club, Saint Petersburg, Florida Saturday February 13, 2016 to Tuesday February 16, 2016



JOHNS HOPKINS ALL CHILDREN'S HOSPITAL







Submit your paper online http://mc.manuscriptcentral.com/cty

CAMBRIDGE UNIVERSITY PRESS

Cardiology in the Young

journals.cambridge.org/CTY

Editor-in-Chief

Editor-in-Chief Jeffrey P. Jacobs, MD, FACS, FACC, FCCP Professor of Surgery and Pediatrics, Johns Hopkins University Chief, Division of Cardiovascular Surgery Director, Andrews/Daicoff Cardiovascular Program Surgical Director of Heart Transplantation and Extracorporeal Life Support Programs, Johns Hopkins All Children's Hospital Past Editor-in-Chief

Edward Baker, MD, FRCP, FRCPCH Medical Director, Oxford Radcliffe Hospitals NHS Trust John Radcliffe Hospital, Headington, Oxford, OX3 9DU, UK **Emeritus Founding Editors**

Professor Robert H. Andersor ersity College, London, UK Dr G. William Henry University of North Carolina at Chapel Hill, USA Senior Associate Editor for Surgery Henry L. Walters III, MD Children's Hospital of Michigan, USA

Senior Associate Editor for Cardiology Allen D. Everett, MD, FACC, FSCAI, FAPS Johns Hopkins University, Baltimore, USA

Associate Editor for Surgery James D. St. Louis, MD University of Missouri-Kansas City School of Medicine, USA Associate Editor for Cardiology Rodney C.G. Franklin, MD, FRCP, FRCPCH Royal Brompton & Harefield Hospital NHS Foundat Trust, UK Associate Editor for Critical Care

John M. Costello, MD, MPH Northwestern University Feinberg School of Medicine, USA Associate Editor for Interventional Cardiology Kevin D. Hill, MD, MSCI Duke University, USA

Associate Editor for Nursing Patricia Hickey, PhD, MBA, RN, FAAN, NEA-BC Boston Children's Hospital, USA

Associate Editor for Mentorship Shakeel Ahmed Qureshi, MBCHB, FRCP, FRCPCH Evelina Children's Hospital, UK

Associate Editor for Cultural, Ethical, and Humanitarian Affairs Professor Tom R. Karl University of Queensland; Mater Children's Hospital, Australia

Associate Editor for Interdisciplinary Collaboration Gil Wernovsky, MD, FAAP, FACC Miami Children's Hospital, USA

Supplements Editor Jeffrey P. Jacobs, MD, FACS, FACC, FCCP All Children's Hospital, Johns Hopkins University, Saint Petersburg, Tampa, and Orlando, USA

Images Editor Dr Roxane McKay Minnesota, USA

International Editor Professor Hiromi Kurosawa

Tokyo Women's Medical University, Japan Founding Editors

Professor Anton Becker Amsterdam, Netherlands Dr Giancarlo Crupi Ospedale Riuniti (Bergamo), Italy Dr Arthur Garson, Jr University of Virginia, Charlottesville, USA Dr Fernando Lucchese Hospital São Francisco, Porto Alegre, Brazil Professor Michael Tynan London, UK

International Editorial Board Professor Lindsey Allan King's College Hospital, London, UK Dr Maurice Beghetti Hôpital des Enfants, Geneva, Switzerland Dr Lee Benson Hospital for Sick Children, Toronto, Canada Dr Per Bjørnstad Dr Anthony Chang Children's Hospital of Orange County, USA

Professor Tjark Ebels Academisch Ziekenhuis Groningen, The Netherlands Dr Timothy Feltes Ohio State University, Columbus, USA Dr J William Gaynor The Chidren Hospital of Philadelphia (CHOP), USA Dr Allan Goldman Great Ormond Street Hospital Children, London, UK Dr Willem Helbing Sophia Children's Hospital, Rotterdam, Netherlands Professor Dohn Hess Sophia Children's Hospital, Kotteruani, Excusion Professor John Hess Deutsches Herzzentrum München, Germany Dr Eero Jokinen Helsinki University Children's Hospital, Finland Professor Hiromi Kurosawa Tokyo Women's Medical University, Japan Tokyo Women's Medical University, Japan Dr Doff B McElhinney Stanford University Medical Center, Palo Alto, USA Dr Luc Mertens The Hospital for Sick Children, Toronto, Canada Dr Cleonice de C Mota Universidade Federal de Minas Gerais, Belo Horizonte, Brazil Universidade Federal de Jonan Dr Jane Newburger Boston Children's Hospital, Boston, USA Dr Edgardo Ortiz Philippine Children's Medical Center, Quezon City, Philippine Children's Medical Center, Quezon Cit Philippines Professor Daniel Penny Texas Children's Hospital, Houston, Texas, USA Dr Andrew Redington The Hospital for Sick Children, Toronto, Canada Dr Girish Shirali Medical University of South Carolina, Charleston, USA Medical University of South Carolina, Dr Norman Silverman Stanford University Medical Center, Palo Alto, USA Dr Giovanni Stellin Universita di Padova, Italy Dr Andras Szatmari Hungarian Center for Pediatric Cardiology, Budapest, Hungary Dr Hideki Uemura Royal Brompton Hospital, London, UK Dr Steven Webber ersity, Nashville, Tennessee, USA Vanderbilt University, N Dr James Wilkinson al Children's Hospital, Melbourne, Australia Dr Shi-Joon Yoo Hospital for Sick Children, Toronto, Canada New Members of International Editorial Board Professor Vera Aiello University of São Paulo Medical School, Brazil Dr Zohair Al Halees King Paial Specialist Hospital & Research Centre, Saudi Arabia Saudi Arabia Dr Marie Josée Hélène Béland Montreal Children's Hospital, Canada Dr. Paul Andrew Checchia Texas Children's Hospital, Houston, Texas, USA Professor M. Sertac Cicel Anadolu Health Foundation Turke Anadou Health Foundation, Jurkey Dr Mitchell Cohen Phoenix Children's Hospital, USA Dr Steven Colan Boston Children's Hospital, Boston, Massachusetts, USA Boston Children's riospital, Doston, J. Dr David Cooper Cincinnati Children's Hospital Medical Center, USA Professor William Michael DeCampli Arnold Palmer Hospital for Children, Florida, USA Dr Christopher Thomas Hugo-Hamman Christiaan Barnard Memorial Hospital, South Africa Dr Krishna Iyer Fortis Escorts Heart Institute and Research Centre, India Fortis Escors Heart Institute and research Centre, India Dr Parvathi Iyer Fortis Escors Heart Institute and Research Centre, India Dr Otto Krogmann Heart Center Duisburg, Germany Dr Peter Laussen Hospital for Sick Children, Toronto, Canada Hospital for Sick Children, Toronto, Canada **Professor Bohdan Jarosław Maruszewski** Children's Memorial Health Institute, Poland Children's Memorial Health Institute, Poland Professor Stephen Seslar University of Washington, USA Professor Narayanswami Sreeram University Hospital of Cologne, Germany Dr James D. St. Louis University of Minnesota, USA Professor Christo Ivanov Tchervenkov The Montreal Children's Hospital, Canada Dr. Paul Weinherg The Montreal Children's Hospital, Canada Dr Paul Weinberg The Children's Hospital of Philadelphia (CHOP), USA Gary Stapleton, MD Johns Hopkins All Children's Heart Institute, Saint Petersburg, Florida

Dr Vijay Anand, MD, FRCPC Stollery Children's Hospital Edmonton Dr Frédérique Bailiard, MD MS n, Alberta, Canada Bailliard Henry Pediatric Cardiology PLLC Raleigh, North Carolina, United States of America Mervl Sahn Cohen, MD Meryl Sahn Cohen, MD Children's Hospital of Philadelphia Philadelphia, Pennsylvania, United States of America Dr Kristine Jane Guleserian MD UT Southwestern Medical Center, Children's Medical Center Dallas Dallas, Texas, United States of America Dr Marina Louise Hughes (née Barbour), MBBS, D.Phil, MRCP (UK), FRACP – Paediatric Cardiology Great Ormond Street Hospital, London, United Kingdom Great Ormond Street Hospital, London, **Dr Leo Lopez, MD** Miami Children's Hospital Miami, Florida, United States of America Miami, Horida, United States of America Dr Charles W. Shepard, MD University of Minnesota Medical School Minneapolis, Minnesota, United States of America Dr Shubhika Srivastava, MBBS Division of Pediatric Cardiology Mount Sinai Medical Center, New York, NY, United States of America Committee on Mentorship Shakeel Ahmed Qureshi, MBCHB, FRCP, FRCPCH Evelina Children's Hospital, UK Jeffrey P. Jacobs, MD, FACS, FACC, FCCP Jeffrey P. Jacobs, MD, FACS, FACC, FC All Children's Hospital, Johns Hopkins Unive Sain Petersburg, Tampa, and Orlando, USA Dr Lee Benson Hospital for Sick Children, Toronto, Canada Dr Rai Anjos CUF Descobertas Hospital, Portugal CUF Descobertas Hospital, Portu Dr Bharat Dalvi Glenmark Cardiac Centre, India Dr Kuberan Pushparajah Evelina Children's Hospital, UK Dr Gurleen Sharland Evelina Children's Hospital, UK Evelina Children's Hospital, UK AEPC Representation Professor Lindsey Allan King's College Hospital, London, UK Dr Rui Anjos CUF Descobertas Hospital, Portugal CUE Descobertas Hospital, Fortugal Edward Baker, MD, FRC2, FRCPCH Oxford Raddlife Hospitals NHS Trust, Oxford, UK Professor Anton Becker Amsterdam, Netherlands Dr Maurice Begherui, Switzerland Höpital des Enfants, Geneva, Switzerland Dr Per Bjørnstad Dr Giancarlo Crupi Ospedale Rimiti (Bergamo), Italy Rodney C.G. Franklin, MD, FRCP, FRCPCH Royal Brompton & Harefield Hospital NHS Foundat Trust, UK Dr Allan Goldman Great Ormond Street Hospital Children, London, UK Dr Willem Helbing Sophia Children's Hospital, Rotterdam, Netherlands Professor John Hess Deutsches Herzzentrum München, Germany Deutsches Fierzzeitum Andersen, Dr Eero Jokinen Helsinki University Children's Hospital, Finland Helsinki Üniversity Children's Hospital, Finland Dr Otto Krogmann Heart Center Duisburg, Germany Dr Kuberan Pushparajah Evelina Children's Hospital, UK Shakeel Ahmed Qureshi, MBCHB, FRCP, FRCPCH Evelina Children's Hospital, UK Dr Gurleen Sharland Evelina Children's Hospital, UK Professor Narayanowami Sreeram University Hospital of Cologne, Germany Dr Andras Szatmari Hungarian Center for Pediatric Cardiology, Budapest, Hungarian Center for Pediatric Cardiology, Budapest. Hu Hungary Professor Michael Tynan Dr Hideki Uemura Royal Brompton Hospital, London, UK **ISNPCHD Representation ISNPCHD – NWG** Professor Vera Aiello University of São Paulo Medical School, Brazil Dr Marie Josée Hélène Béland Montreal Children's Hospital, Canada Dr Steven Colan Boston Children's Hospital, Bost on, Massachusetts, USA Rodney C.G. Franklin, MD, FRCP, FRCPCH Royal Brompton & Harefield Hospital NHS Foundatior Trust, UK

Jeffrey P. Jacobs, MD, FACS, FACC, FCCP All Children's Hospital, Johns Hopkins University, Petersburg, Tampa, and Orlando, USA Petersburg, Lampa, and Orlando, USA Dr J William Gaynor The Children's Hospital of Philadelphia (CHOP), USA **Professor Fluromi Kurosawa** Tokyo Women's Medical University, Japan Dr Otto Krogmann Heart Center Duisburg, Germany Paefore in Burger, Bernany Professor Bohdan Jarosław Maruszewski Children's Memorial Health Institute, Poland Children's Memorial Health Institute, Poland Dr Giovanni Stellin Universita di Padova, Italy Professor Christo Ivanov Tchervenkov The Montreal Children's Hospital, Canada Dr Paul Weinberg The Children's Hospital of Philadelphia (CHOP), USA ISNPCHD - Additional Representation

Professor Robert H. Anders University College, London, UK Allen D. Everett, MD, FACC, FSCAI, FAPS Johns Hopkins Univ Jonns Hopkins University, Baltimore, I Henry L. Walters III, MD Children's Hospital of Michigan, USA Professor Stephen Seslar University of Washington, USA Dr James D. St. Louis University of Minnesota, IISA Dr Frédérique Bailliard, MD MS Bailliard Henry Pediatric Cardiology PLLC Raleigh, North Carolina, United States of America Meryl Sahn Cohen, MD Meryl Sahn Cohen, MD Children's Hospital of Philadelphia Philadelphia, Pennsylvania, United States of America Dr Kristine Jane Guleserian MD UT Southwestern Medical Center, Children's Medical Center Dallas Dallas, Texas, United States of America Dr Marina Louise Hughes (née Barbour), MBBS, D.Phil, MRCP (UK), FRACP – Paediatric Cardiology Cento Pumod Street Hospital, London, United Kingdom et Hospital, London, United Kingdo Great Ormond Street Hospital, London, United Kinge Dr Leo Lopez, MD Miami, Children's Hospital Miami, Florida, United States of America Dr Charles W. Shepard, MD University of Minnesota Medical School Minneapolis, Minnesota, United States of America Dr Shubhika Srivastava, MBBS Division of Pediatric Cardiology Mount Sinai Medical Center, New York, NY, United States of America PCICS Representation

Dr. Paul Andrew Checchia Dr. Paul Andrew Checchia Texas Children's Hospital, Houston, Texas, USA Dr David Cooper Cincinnati Children's Hospital Medical Center, USA John M. Costello, MD, MPH Northwestern University Feinberg School of Medicine, USA Dr Allan Goldman at Ormond Street Hospital Children London UK Great Ormond Street Hospital Children, London, UK Jeffrey P. Jacobs, MD, FACS, FACC, FCCP All Children's Hospital, Johns Hopkins University, Saint Petersburg, Tampa, and Orlando, USA Dr Parvathi Iyer Fortis Escors Heart Institute and Research Centre, India Dr Peter Laussen Hospital for Sick Children, Toronto, Canada WCPCCS Representation

Dr Zohair Al Halees King Faisal Specialist Hospital & Research Centre, Saudi Arabia Dr Lee Benson Hospital for Sick Children, Toronto, Canada Professor M. Sertac Cicek Anadolu Health Foundation, Turkey Anadolu Health Foundation, lurkey Dr. Christopher Thomas Hugo-Hamman Christian Barnard Memorial Hospital, South Afri Jeffrey P Jacobs, MD, FACS, FACC, FCCP All Children's Hospital, Johns Hopkins University, Saint Petersburg, Tampa, and Orlando, USA Professor Tom R. Karl Universiti of Children's Horpic Africa University of Queensland; Mater Children's Hospital, Australia Professor Hiromi Kurosawa Tokyo Women's Medical University, Japan Tokyo Women's Medical University, Japan Dr Krishna Iyer Fortis Escors Heart Institute and Research Centre, India Shakeel Ahmed Qureshi, MBCHB, FRCP, FRCPCH Evelina Children's Hospital, UK Gil Wernovsky, MD, FAAP, FACC Miami Children's Hospital, USA Dr James Wilkinson Royal Children's Hospital, Melbourne, Australia

Cardiology in the Young is indexed and abstracted in Index Medicus/MEDLINE; Current Contents/Clinical Medicine; Research Alert; Sci Search; EMBASE/Excerpta Medica

Commissioning Editor: Dan Edwards Production Editor: Nicki Marshall

Design and Production: MPS Limited, Bangalore Printed & Bound: The Sheridan Press, USA.

Published by Cambridge University Press (Journals), UPH, Shaftesbury Road, Cambridge CB2 8BS, UK Tel: +44 (0)1223 326491; Fax: +44 (0)1223 325802; E-mail: dedwards@cambridge.org

Cambridge Core

For further information about this journal please go to the journal website at: cambridge.org/cty

DECEMBER 2016 ISSUE OF CARDIOLOGY IN THE YOUNG:

Highlights of HeartWeek 2016



JOHNS HOPKINS ALL CHILDREN'S HOSPITAL



Johns Hopkins All Children's Hospital Andrews/Daicoff Cardiovascular Program 2016 Summit: Postgraduate Education in Pediatric and Congenital Cardiac Care Renaissance Vinoy Resort & Golf Club, Saint Petersburg, Florida Thursday, February 11, 2016 and Friday, February 12, 2016

and

Johns Hopkins All Children's Hospital 16th International Symposium on Congenital Heart Disease Special Focus: Pediatric and Congenital Diseases of the Aorta Co-Sponsor: The American Association for Thoracic Surgery (AATS) Renaissance Vinoy Resort & Golf Club, Saint Petersburg, Florida Saturday February 13, 2016 to Tuesday February 16, 2016

Editor:

Jeffrey P. Jacobs, M.D., FACS, FACC, FCCP Editor-in Chief, Cardiology in the Young Professor of Surgery and Pediatrics, Johns Hopkins University

Chief, Division of Cardiovascular Surgery Director, Andrews/Daicoff Cardiovascular Program Surgical Director of Heart Transplantation and Extracorporeal Life Support Programs Johns Hopkins All Children's Heart Institute Johns Hopkins All Children's Hospital and Florida Hospital for Children

EDITORIAL Board:

Jeffrey P. Jacobs, Marshall L. Jacobs, Tom R. Karl, Constantine Mavroudis, Melvin C. Almodovar, and Gary E. Stapleton

Jacobs JP, Jacobs ML, Karl TR, Mavroudis C, Almodovar MC, Stapleton GE. (Editors). December 2016 Issue of Cardiology in the Young: Annual Heart Week in Florida Issue Number 14 - **Highlights of HeartWeek 2016: Postgraduate Education in Pediatric and Congenital Cardiac Care and Pediatric and Congenital Diseases of the Aorta**. Cardiology in the Young, Volume 26, Issue 8, pages 1455–1602, December, 2016.

6th Scientific Meeting of the

World Society for Pediatric and Congenital Heart Surgery

Hosted by Johns Hopkins All Children's Hospital



July 23-26, 2018 Walt Disney World • Orlando, Florida

Mark your calendar for the 2018 Scientific Meeting of the World Society for Pediatric and Congenital Heart Surgery. We hope you can join this premier gathering of the largest professional organization in the world dedicated to pediatric and congenital cardiac surgery. In keeping with the WSPCHS mission, presenters at this meeting will strive to promote the highest quality comprehensive care to all patients with congenital heart disease, from the fetus to the adult regardless of the patient's economic means, with an emphasis on excellence in teaching, research and community service.



Program Chairs: Jeffrey P. Jacobs, MD and Marshall L.. Jacobs, MD Johns Hopkins All Children's Hospital Johns Hopkins University For more information:

www.WSPCHS20l8.com



0.1017/S104795111700021X Published online by Cambridge University Press



8th World Congress of Pediatric Cardiology and Cardiac Surgery SEPTEMBER 19-24, 2021 WASHINGTON D.C.

> In 2021, for the first time ever, the World Congress of Pediatric Cardiology and Cardiac Surgery will be held in the continental United States of America.

The 2021 WCPCCS promises to be the most comprehensive, up-to-date and technologically advanced meeting ever conceived for Pediatric and Congenital Heart Disease.

15 SUBSPECIALTY TRACKS

Cardiac Surgery • Ambulatory Cardiology and Acquired Heart Disease • Imaging • Electrophysiology • Catheterization Adult Congenital Heart Disease • Heart Failure and Transplantation • Cardiac Intensive Care • Cardiac Anesthesia • Cardiac Nursing Perfusion and Mechanical Support • Basic Science • Orphan Topics • Administration • Special Sessions for Trainees

Co-Chairs

Jeffrey P. Jacobs, MD • Johns Hopkins All Children's Hospital Gil Wernovsky, MD • Nicklaus Children's Hospital, Miami Children's Health System

WCPCCS2021.org

Volume 26 • Number 8 • Pages 1455–1602

Cardiology in the Young

COPYRIGHT © 2016 CAMBRIDGE UNIVERSITY PRESS ISSN 1047-9511

Table of ContentsDecember 2016

Highlights of HeartWeek 2016 - Proceedings of:

Johns Hopkins All Children's Hospital Andrews/Daicoff Cardiovascular Program 2016 Summit: Postgraduate Education in Pediatric and Congenital Cardiac Care Renaissance Vinoy Resort & Golf Club, Saint Petersburg, Florida Thursday, February 11, 2016 and Friday, February 12, 2016 and Johns Hopkins All Children's Hospital 16th International Symposium on Congenital Heart Disease Special Focus: Pediatric and Congenital Diseases of the Aorta Co-Sponsor: The American Association for Thoracic Surgery (AATS)

Renaissance Vinoy Resort & Golf Club, Saint Petersburg, Florida Saturday February 13, 2016 to Tuesday February 16, 2016

Editor:

Jeffrey P. Jacobs

Obituary		
In Memoriam: Professor Dr Christian Schreiber Ruediger Lange	1455	
Book Review		
Stark choices: A surgeon's story: from Prague to London and beyond <i>Jeffrey P. Jacobs</i>	1457	
Part 1: Proceedings of Johns Hopkins All Children's Heart Institute Andrews/Daicoff Cardiovascular Program 2016 Summit: Postgraduate Education in Pediatric and Congenital Cardiac Care		
What's new in graduate medical education? Raquel G. Hernandez	1459	
Paediatric cardiac surgical education: which are the important elements? <i>Tom R. Karl, Jeffrey P. Jacobs</i>	1465	
Training in paediatric cardiac surgery and the American Board of Thoracic Surgery <i>Edward L. Bove</i>	1471	
Training fellows in paediatric cardiac surgery <i>Richard A. Jonas</i>	1474	
Training cardiac surgeons: the Indiana University experience John W. Brown	1484	
Training in paediatric cardiac surgery: the history and role of training in a different country and even overseas <i>Martin J. Elliott</i>	1491	
The past, present, and future of paediatric cardiology training at the Johns Hopkins Hospital, in the tradition of Dr Helen Taussig	1494	
Gary S. Beasley, Anne M. Murphy, Joel I. Brenner, William J. Ravekes		

Table of Contents continued

	Training fellows in paediatric cardiology: the Harvard experience David W. Brown, Catherine K. Allan, Jane W. Newburger	1499
	Training residents/fellows in paediatric cardiology: the Emory experience <i>Robert M. Campbell</i>	1507
	Training of residents and fellows: the Mayo Clinic experience David Driscoll	1511
	A Pediatric Cardiology Fellowship Boot Camp improves trainee confidence Catherine K. Allan, Paul Tannous, Elizabeth DeWitt, Michael Farias, Laura Mansfield, Christina Ronai, David Schidlow, Stephen P. Sanders, James E. Lock, Jane W. Newburger, David W. Brown	1514
	Finding time and resources for education in a busy clinical practice <i>David Driscoll</i>	1522
	Training residents and fellows in paediatric cardiac anaesthesia Dean B. Andropoulos	1525
	Training fellows and residents in paediatric cardiac critical care Sarah Tabbutt, Nancy Ghanayem, Melvin C. Almodovar, John Charpie, Stephen J. Roth, James Fortenberry, Ron Bronicki	1531
	2: Proceedings of Johns Hopkins All Children's Heart Institute 16th International Symposium Congenital Heart Disease: Special Focus – Pediatric and Congenital Diseases of the Aorta	
	Primary-care management of patients with coarctation of the aorta Jeffrey R. Boris	1537
	Assessment of the structure and function of the aorta by echocardiography <i>Anitha Parthiban, Girish Shirali</i>	1543
	Echocardiography of coarctation of the aorta, aortic arch hypoplasia, and arch interruption: strategies for evaluation of the aortic arch <i>Suma P. Goudar, Sanket S. Shah, Girish S. Shirali</i>	1553
	Transcatheter intervention for coarctation of the aorta Matthew E. Zussman, Russel Hirsch, Carrie Herbert, Gary E. Stapleton	1563
	The use of a three-dimensional print model of an aortic arch to plan a complex percutaneous intervention in a patient with coarctation of the aorta Nalini Ghisiawan, Carrie E. Herbert, Matthew Zussman, Adam Verigan, Gary E. Stapleton	1568
	Ethical considerations of transparency, informed consent, and nudging in a patient with paediatric aortic stenosis and symptomatic left ventricular endocardial fibroelastosis <i>Constantine D. Mavroudis, Thomas Cook, Jeffrey P. Jacobs, Constantine Mavroudis</i>	1573
Dant		
Part	3: Select visionary manuscripts related to pediatric and congenital cardiac care Utility of 4D Flow mapping in Eisenmenger syndrome with pulmonary atresia Soba Romeih, Heba Aguih, Magdi Yacouh	1581
	Design and initial results of a programme for routine standardised longitudinal follow-up after congenital heart surgery Sara K. Pasquali, Chitra Ravishankar, Jennifer C. Romano, Kristin Kane, Suzanne Viers, Andrea Kennedy, Nancy Burnham, Ray Lowery, Karen Uzark, Lauren Retzloff, Jonathon J. Rome, Joseph W. Rossano, John R. Charpie, Thomas L. Spray, Michael G. Gaies, Richard G. Obye, J. William Gaynor	1590
	Big Data and paediatric cardiovascular disease in the era of transparency in healthcare Alfred Asante-Korane, Jeffrey P Jacobs	1597

Alfred Asante-Korang, Jeffrey P Jacobs

This journal issue has been printed on FSC-certified paper and cover board. FSC is an independent, non-governmental, not-for-profit organization established to promote the responsible management of the world's forests. Please see www.fsc.org for information

Cardiology in the Young © 2016 Cambridge University Press, ISSN 1047-9511 is published bi-monthly

Subscription information: Volume 26 (8 issues) will appear in 2016. Correspondence concerning subscriptions should be addressed to: Journals Customer Services, Cambridge University Press, UPH, Cambridge CB2 8BS, UK, Tel: +44 (0)1223 326107; Fax: +44 (0)1223 325150; E-mail enquiries: journals_subscriptions@cambridge.org; Web: www.cambridge.org; Cambridge Journals Online: www.journals.cambridge org/cty. The subscription are for 2016 Volume 26 (8 issues) is: Institutional electronic only rate £1205 or US\$2049. Cheques should be made payable to Cambridge University Press. Copyright: The submission of a manuscript is accepted for publication, each work described has not been published before, except in the form of an abstract or as part of a publication elsewhere; (c) that all co-authors approve its publication; (d) that its publication is approved by the responsible authorities at the institute where the work has been carried out; (e) that when the manuscript is accepted for publication, eauthors approve its publication; (d) that its publication is approved by the authors for material used from other copyright holders, and (g) that written permission of the copyright holder is obtained by the authors for material used from other copyrighted sources. All articles published in this journal are protected by copyright, which covers the exclusive rights to reproduce and distribute the article, as well as all translation rights. No material published in this journal are believed to be true and accurate at the date of its going to press, neither the authors, the editors, the publisher, nor any affiliated Society can accept any legal responsibility for any errors or omissions that may be made. The publisher nor any affiliated Society can accept any legal responsibility for any errors or omissions that may be made. The publisher nor any affiliated Society can accept any legal enviresity Press publications advertisements in this journal while relying on the responsibility of right with respect to the material adde of product

Comprehensive, Compassionate Care

Collaboration to advance outcomes.

The Johns Hopkins All Children's Heart Institute in St. Petersburg brings hope to children and families. We deliver high-quality, patient- and family-centered care supported by evidence-based medicine and our commitment to patient safety and quality. Our surgical outcomes are among the best in the nation at every level of surgery, including the most complex procedures.

Johns Hopkins Children's Heart Surgery—One program with three locations. Our team of pediatric cardiovascular surgeons in Florida and Baltimore comprises one of the nation's largest children's heart surgery programs. They work together as one team to pursue new avenues for excellence in clinical care and continue to improve outcomes through research and innovation.

Additional programs include:

- Adult Cardiac Program
- Heart Failure & Transplant Program
- Single Ventricle Syndromes
- Cardiomyopathy
- Fetal Heart Program
- Interventional Cardiology

- Cardiac Arrhythmias
- Preventive Cardiology
- Pulmonary Hypertension
- Vascular Thrombosis Clinic
- Cardiac Neurodevelopmental Care

Learn more at HopkinsAllChildrens.org/Heart

Johns hopkins all children's Heart Institute

We bring HEART to the most advanced care.

all we do. all for kids."

Conservation of the



eari

Association for European Paediatric and Congenital Cardiology (AEPC)



EPC WAS FOUNDED IN LYON IN 1963 (as Association Européenne pour la Cardiologie Pédiatrique) and subsequently has created a network of specialists who are committed to the practice and advancement of Congenital Cardiology and closely related fields. Cardiology in the Young is the official journal of the AEPC. AEPC offers a free subscription of 'Cardiology in the Young' (CitY) as part of the annual membership fee. The membership also offers several other benefits.

The overall membership of the Association currently stands at 1 300 paediatric cardiologists and other specialists working in the field of paediatric cardiology and its related disciplines. As far as we are aware, the AEPC is the largest democratically administered global association in the field of paediatric and congenital cardiology. Members of the AEPC originate from virtually all countries in Europe and it is encouraging that there are now increasing numbers of members from all the continents. New members are very welcome as they bring with them new ideas and innovations.

AEPC and its Working Groups aim to enhance collaboration amongst members for scientific research, promoting training, professional development and to maintain high standards of professional practice. The work on behalf of children and patients with congenital heart diseases is global and the AEPC has made itself a global organisation by its close collaboration with other international organizations. These include the European Society of Cardiology; the Japanese Society of Paediatric Cardiology and Cardiac Surgery (JSPCCS); the European Association for Cardio-Thoracic Surgery (EACTS) and; the Adult Congenital and Pediatric Cardiology Section of the American College of Cardiology (ACC); the Asia Pacific Pediatric Cardiac Society (APPCS); the European Heart Surgeons Association (ECHSA), the World Congress of Paediatric Cardiology and Cardiac Surgery and several others.

Working groups

Several activities of AEPC are organized by the Working Groups. The Working Groups represent different subspecialties and specific areas of paediatric and congenital cardiology. The Association now has 13 Working Groups, to bring together workers with similar interests in order to facilitate research and collaboration and to organise teaching and training.

Annual meetings

An Annual Meeting and an Update-On Course are organised by the AEPC, usually in the third week of May in collaboration with one of the member countries. The AEPC organizes 2–3 Teaching courses for trainees in Paediatric Cardiology each year. Additional symposia and courses are usually a part of the annual meetings.

The International Society for Nomenclature of Paediatric and Congenital Heart Disease



HE INTERNATIONAL SOCIETY FOR NOMENCLATURE of Paediatric and Congenital Heart Disease (ISNPCHD) is an established not-for-profit organization, with the collective mission to identify, standardize, and maintain an international system of nomenclature, the International Paediatric and Congenital Cardiac Code (IPCCC), to enhance global communication and facilitate patient care, research, and training in paediatric and congenital cardiac care across disciplines. In other words, the IPCCC provides a common language and terminology, inclusive of definitions and imaging, which covers the entire field of diagnostic and procedural terms for paediatric and congenital heart care. The IPCCC is the product of the cross-mapping work by the ISNPCHD Nomenclature Working Group during the decade following the publication in 2000 of two similar and complementary nomenclature systems, namely the International Congenital Heart Surgery Nomenclature and Database Project under the auspices of the European Association for Cardio-Thoracic Surgery and Society of Thoracic Surgeons, and the European Paediatric Cardiac Code under the auspices of the Association for European Paediatric Cardiology. The IPCCC is owned by the ISNPCHD but is digitally published for free download for private use (www.ipccc.net) in these two Societal versions, both with a Long List of over 10,000 terms with qualifiers, and a Short List of up to 1000 terms for use in databases when comparing institutional outcomes, both nationally and internationally. The Long Lists of the IPCCC comprehensively cover the field of paediatric and congenital cardiac care, including diagnoses of congenital and related acquired pathology, comorbid conditions, transcatheter and operative procedures, and a full list of postprocedural complications. The Short Lists are used within databases across the world with over 500,000 registered patients. The ISNPCHD encourages the commercial use of the

IPCCC by requiring and providing free-of-charge license agreements for its use, to ensure that the IPCCC remains unaltered by parties other than the ISNPCHD.

Since 2007 the ISNPCHD has been operating through three working groups:

- The Nomenclature Working Group, which continues to maintain, develop, expand, update, and preserve the IPCCC;
- The Definitions Working Group, which is engaged in writing definitions for the terms in the IPCCC. More recently this initiative has focused on the terms provided by the ISNPCHD at the behest of the World Health Organization (WHO) for the 11th revision of the International Classification of Diseases;
- The Archiving Working Group, which is engaged in linking images and videos to the IPCCC, including cardiac morphologic specimens, echocardiography, angiography, computerized axial tomography, magnetic resonance imaging, intraoperative photographs and intraoperative videos.

The ISNPCHD, through the IPCCC, enables institutions from around the world to seamlessly communicate with each other, comparing and then improving outcomes and the quality of care that is given to children, young people, and adults born with malformed hearts. This common language enables institutions to learn from those hospitals performing best at a global level, as well as facilitating research projects, such as comparing the longer term quality of life and complications in those who have required operative and transcatheter interventions. In addition, the nomenclature with corresponding definitions and matching imaging, enhances teaching of this specialty to the next generation of clinicians dedicated to pediatric and congenital cardiac care, both in the developed and developing world.