MESSAGE from LEADERSHIP

This past year has been one of phenomenal growth in the Adult Congenital Heart Association. In our leadership roles as Board Chair and National Executive Director, we have been humbled by the passion, strength and commitment of the many thousands of members and supporters throughout the country.

In 2014, we hosted our national conference where more than 500 patients, families and medical community members joined in sessions on medical procedures, health insurance insights, medical provider/patient communications and much more. The shared insights from this broad representation of the CHD community were unique and powerful.

Our website traffic and webinar participation continues to grow. This year more than 120,000 participants accessed our site and attended webinars on CHD-related topics. Although it continues to be a challenge to reach those “hard to care,” we are now reaching more ever through these programs.

Our Medical Advisory Board has built a template for the Accreditation Program that when implemented can change the landscape of ACHD care across the country. Many thanks to Drs. Curt Daniels and Jami Aboulhosn for their leadership in this process.

2014 by the NUMBERS
FISCAL YEAR ENDED DECEMBER 31, 2014 (IN USD)

PUBLIC SUPPORT AND OTHER REVENUE 2014 2013
Contributions 1,268,084 1,107,083
Grants 614,700 294,202
Program & Events (conference, publications, regional events) 150,461 90,460
Dues 19,090 19,446
Contract (sub grants) 0 0
Other (merchandise, interest) 5,015 3,999
Subtotal Revenue Public Support and Other Revenue 2,057,850 1,516,089
Prior Year revenue reserved for This Year Operation 770,123 0
Total Public Support and Other Revenue (Gross) 2,827,973 1,516,089
Revenue restricted for next year’s operations and long term funds (Net Assets) 974,035 770,123
Total Public Support and Other Revenue (Net) 1,853,938 745,966

EXPENSES 2014 2013
Education 1,346,772 948,327
Advocacy/Outreach 120,096 166,345
Research 21,366 43,198
Fundraising 146,124 159,649
Administration 219,580 256,265
Total Expenses 1,853,938 1,572,774

ACHA 2014 Board of the 2014 National Conference, from left: Operations Manager Janice Fydey, National Executive Director Glenn R. Tringali, Director of Programs Danielle Stephens, Member Services Manager Pauls Miller, Development Assistant Ashley Sheehan, Development Manager Annie DiGiovanni, Communications Manager Terri Schneider, and Volunteer Coordinator Egan Callen.

EXPENSES, STRATIFIED 2014 2013
Concetional Heart Walks 472,429 368,756
Professional Education Programs 220,043 242,422
Advocacy Activities 93,223 115,671
Patient/Family Member Services 98,006 132,619
H2H Ambassadors Program 82,716 97,275
Educational Events 50,561 70,245
Outreach Activities 26,872 50,674
Research 21,366 43,198
National Conference 403,018 36,560
Total Programs 1,488,234 1,157,870
Total Fundraising 146,124 159,649
Strategic planning 33,474 43,198
Administration 186,106 210,542
Total Management 219,580 256,265
Total Expenses, Stratified 1,853,938 1,572,774

VALUES
We believe in the following shared principles, beliefs and priorities:

Patient Empowerment. We believe that those affected by congenital heart disease need to be heard and that they are powerful advocates for our community.

Commitment to Excellence. We believe in providing resources and information to qualified professionals and in promoting quality healthcare for the congenital heart community.

Patient-Provider Partnerships. We believe in medical professionals and patient working together to promote health in our community.

Collaboration. We believe in individuals and organizations working together to collaborate efforts to achieve common goals in the patient’s interest.

Leadership for Change. We believe that we play a lead role in creating a better future for congenital heart patients.

VISION
ACHA will be the leading voice in congenital heart disease education and advocacy, and raise the public awareness of congenital heart disease as a lifelong disease. ACHA will improve the standards for access to and delivery of care for adults with congenital heart disease. ACHA in collaboration with our partners will drive the public policy agenda affecting adults with congenital heart disease.

2014 MEMBERSHIP SNAPSHOT
Total number of ACHA members as of December 31:
• 8,995 patient/family
• 1,369 medical professionals

In total during the year, ACHA had: 1.15% growth
“A portion of these doctors are also ACHA patient/family and professional members.

ACHA ANNUAL REPORT | 2014 3
ACHA Blog

Hearts, this 2014 ACCOMPLISHMENTS

ACHA is privileged to continue to work collaboratively with leading professional organizations and federal agencies to address CHD in the context of public health to improve awareness, education, and advocacy for the CHD community and the general public.

NATIONAL CONGENITAL HEART ADVOCACY DAY

More than 50 advocates gathered in Washington, D.C. at the end of Heart Month for this incredible opportunity to talk to their lawmakers about CHD. Hosted by ACHA and Mended Little Hearts, this annual event brought together parents, family members, medical professionals, and supporters from across the country to connect with more than 70 legislative offices.

On February 26, advocates received training and attended the well-received presentation at the American College of Cardiology’s Heart House. On February 27, advocates spent a full day on the Hill asking their legislators to support National Institutes of Health funding and Centers for Disease Control and Prevention surveillance efforts, as well as recruiting House members for the Congressional Congenital Heart Caucus (an informal group of members of Congress to specialize in caring for adults with CHD). Current standard cardiology training dictates residents receive only six hours of general CHD lectures and no requirement to treat a single CHD patient. Current standard cardiology training dictates residents receive only six hours of general CHD lectures and no requirement to treat a single CHD patient. Current standard cardiology training dictates residents receive only six hours of general CHD lectures and no requirement to treat a single CHD patient.

LOCAL HEART HAPPENINGS

ACHA had another successful year of Heart to Heart Where You Live Regional Events, where selected Advocates, along with regional adult congenital heart disease (ACHD) medical programs, hosted informal education meetings. Four meetings, with 204 total attendees, occurred in 2014—St. Louis, San Francisco, Atlanta and New York City. ACHA staff members and Advocates also participated and exhibited at a number of conferences and venues, including community health fairs and lifelong care educational events for parents of children with congenital heart disease (CHD), reaching nearly 450 people.

WEBINARS

More than 750 individuals attended 13 different webinars in 2014. National experts spoke on a variety of defect specific topics, and others educate other members and their constituents on this subject (such as “Coping Tips for ACHD Spouses and Family Members” and “Exercise and ACHD: From Testing to Treatment.” Online views of archived webinars in 2014 totaled about 2,200.

FELLOWSHIP AWARD

In 2014 an ACHA Action Fellowship Award was given to the University of California Los Angeles, which now joins Stanford University as the second awarded site. This award will be used to provide two years of special training for cardiologists wishing to specialize in caring for adults with CHD. Current standard cardiology training dictates residents only receive six hours of general CHD lectures and no requirement to treat a single CHD patient. However, the American Board of Medical Specialties recently created a special adult CHD pathway that will require adult CHD specialists to complete seven years of adult and pediatric congenital heart training and complete a subspecialty exam. Accreditation is a process in which individual ACHD programs undergo careful review to make certain that they provide a standard of quality care to ACHD patients based on published guidelines and standards. In response to ACHA’s commitment to improving the quality of care for every U.S. ACHD patient, ACHA convened the first ACHD program Accreditation Steering Committee meeting in 2014 to discuss and develop criteria for two levels of ACHD Programs: an ACHD Comprehensive Care Center and an ACHD Care Center. Rollout of this program will occur in late 2015.

ACHA is proud of all our accomplishments this year; some highlights are provided on these two pages.

ACHD TRAVEL DIRECTORY AND ONLINE PROGRAM DIRECTORY

In continued collaboration with the International Society of Adult Congenital Heart Disease (ISACHD), ACHA offers a print listing of CHD services that includes hundreds of sites worldwide capable of providing emergency ACHD care to CHD patients. Also in collaboration with ISACHD, ACHA continues to offer an online listing of more than 120 ACHD clinics in the United States and Canada; the directory continues to be the only resource of its kind available in the online and to support, honor, and remember the millions affected by CHD.

To join in our efforts, visit www.congenitalheartwalk.org and to support, honor, and remember the millions affected by CHD.

MEMBERSHIP AND SUPPORT

2014 MEDICAL PROFESSIONAL MEMBERS

January 1, 2014 to December 31, 2014

ACHA Medical Professional Members not only support the vital work ACHA does to improve health for adults with CHD, but also demonstrate that as medical professionals, they have a vital role in ACHA’s mission! Below includes all paid professional members of ACHA for 2014. ACHA is proud of all our accomplishments this year; some highlights are provided on these two pages.

ACHA ONLINE BY THE NUMBERS

Website

370,589 page views

ACHA Blog

100 posts published in 2014

Facebook

5,735 followers by year’s end

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2014 ACCOMPLISHMENTS

ACHA IS PROUD OF ALL OUR ACCOMPLISHMENTS THIS YEAR; SOME HIGHLIGHTS ARE PROVIDED ON THESE TWO PAGES.
2014 HIGHLIGHT

ACHA 7TH NATIONAL CONFERENCE

Our 7th National Conference was held September 5 to 7, 2014, at the Holiday Inn Chicago Mart Plaza in Chicago, Illinois. A total of 513 patients, family members, caregivers, healthcare providers, and researchers attended the conference, which provided a unique opportunity for the entire ACHD community to come together to interact, learn, and build hope for the future.

The overarching theme was Translating Quality of Care into Quality of Life, and the conference offered three overlapping tracks that met separately and together in plenary sessions.

• The Patient/Family Conference offered attendees the chance to learn about managing their disease and related conditions from top national CHD specialists, as well as a unique opportunity to give and receive peer support from others affected by these rare conditions.

• The Research Symposium brought together international CHD researchers, clinicians, patients, and families to address issues in improving outcomes and quality of life; 32 abstracts were presented.

• The Health Professionals Conference allowed healthcare providers with a primary focus in ACHD to strengthen their skills and learn about new strategies for helping their patients.

There was plenty of fun, social, and networking time to be had at the conference, too! Attendees were able to mingle with others at roundtables, meals, the exhibit hall, ACHA Gala, bus trip to Navy Pier, and more.

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Dr. Ray peaceful and serene at home in London, England. 

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Chiba Cardiovascular Center/Japan

www.achaheart.org
info@achaheart.org
888-921-ACHA
3300 Henry Avenue
Suite 112
Philadelphia, PA 19129