In 2013 we continued to make great strides in serving the congenital heart disease community and in nurturing the growth of the Adult Congenital Heart Association. We have made our voice heard in care centers, policy centers and even on the streets! The Congenital Heart Walk has expanded to 27 cities, raising awareness of the need for lifelong congenital heart care. There are now 51 Heart to Heart Ambassadors, ready to provide support and education for our members. And we continue to build our sense of community through social media and regional events.

Amid all this growth we also take time to reflect on where we have come from and look forward to where we are going. This year we said goodbye to Amy Verstappen, as she stepped down from her longtime role as CEO/President. We wish her well on the next chapter of her life and we also share her pride in all that was accomplished under her leadership.

Now we continue on our road with new leadership, recognizing that the strength of ACHA comes from all of us working together, joining our voices. We continue to have an amazing group of staff and volunteers, each of whom is committed to improving and extending the lives of those born with congenital heart defects. I invite you to join us at the 7th National Conference in 2014 to learn, to share experiences, and to celebrate our community.

Peggy Powers
Board Chair
2013 By the Numbers

Fiscal Year Ended December 31, 2013 (in USD)

Public Support and Other Revenue

<table>
<thead>
<tr>
<th>2013</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions</td>
<td>$1,107,983</td>
</tr>
<tr>
<td>Grants</td>
<td>$294,202</td>
</tr>
<tr>
<td>Program &amp; Events (conference, publications, regional events)</td>
<td>$90,460</td>
</tr>
<tr>
<td>Dues</td>
<td>$19,445</td>
</tr>
<tr>
<td>Other (merchandise, interest)</td>
<td>$3,999</td>
</tr>
</tbody>
</table>

Subtotal Revenue Public Support and Other Revenue | $1,516,089 | $1,625,797 |

Prior Year revenue reserved for This Year | $826,808 | $481,122 |

Total Public Support and Other Revenue (Gross) | $2,342,897 | $2,106,919 |

Revenue restricted for next year and long term funds | $770,123 | $826,808 |

Total Public Support and Other Revenue (Net) | $1,572,774 | $1,280,111 |

Expenses

<table>
<thead>
<tr>
<th>2013</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>$948,327</td>
</tr>
<tr>
<td>Advocacy/Outreach</td>
<td>$166,345</td>
</tr>
<tr>
<td>Research</td>
<td>43,198</td>
</tr>
<tr>
<td>Fundraising</td>
<td>$159,649</td>
</tr>
<tr>
<td>Administration</td>
<td>$255,255</td>
</tr>
</tbody>
</table>

Total Expenses | $1,572,774 | $1,280,111 |

Expenses, Stratified

<table>
<thead>
<tr>
<th>2013</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Congenital Heart Walks</td>
<td>$368,756</td>
</tr>
<tr>
<td>Professional Education Programs</td>
<td>$242,422</td>
</tr>
<tr>
<td>Advocacy Activities</td>
<td>$115,671</td>
</tr>
<tr>
<td>Patient/Family Member Services</td>
<td>$132,619</td>
</tr>
<tr>
<td>H2H Ambassadors Program</td>
<td>$97,725</td>
</tr>
<tr>
<td>Educational Events</td>
<td>$70,245</td>
</tr>
<tr>
<td>Outreach Activities</td>
<td>$50,674</td>
</tr>
<tr>
<td>Research</td>
<td>$43,198</td>
</tr>
<tr>
<td>National Conference</td>
<td>$36,560</td>
</tr>
</tbody>
</table>

Total Programs | $1,157,870 | $974,722 |

Total Fundraising | $159,649 | $158,907 |

Strategic Planning | $44,713 | $78,263 |

Total Management | $255,255 | $146,484 |

Total Expenses, Stratified | $1,572,774 | $1,280,111 |

Membership Report as of December 31, 2013

The Adult Congenital Heart Association (ACHA) is a nonprofit organization exempt from income tax under Section 501(c)(3) of the U.S. Internal Revenue Code. ACHA has been classified as an organization that is not a private foundation and has been designated as a publicly supported organization. ACHA will be pleased to provide a copy of its audited financial statement upon request. Visit www.achaheart.org for ACHA's Form 990.
2013 ACHA ACCOMPLISHMENTS

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

HEART TO HEART AMBASSADORS
ACHA expanded both the number of Ambassadors and the Ambassadors’ reach and impact. Twelve new Ambassadors were trained in 2013, bringing the total to 51. Along with ACHA member services staff, Ambassadors offered more than 1,100 ACHA patient and family members personalized information and support.

REGIONAL EVENTS
ACHA launched a regional programming pilot this year, where selected Ambassadors, along with regional adult congenital heart disease (ACHD) medical programs, hosted informal education meetings. Four meetings occurred in 2013—Chicago, IL, Orange County, CA, Portland, OR, and Philadelphia (Delaware Valley), PA. ACHA staff members and Ambassadors also participated and exhibited at a number of conferences and venues, including community health fairs and events for parents of children with congenital heart disease (CHD).

NATIONAL CONGENITAL HEART ADVOCACY DAY
More than 110 advocates gathered in Washington, D.C., on March 19 for this incredible opportunity to talk to their lawmakers about CHD. Hosted by the Adult Congenital Heart Association (ACHA) and Mended Little Hearts (MLH), this annual event brought together patients, family members, medical professionals, and supporters from across the country to connect with 120 legislative offices.

This year’s message rang loud and strong. At Advocacy Day 2013, we asked our lawmakers to provide continued funding to the Centers for Disease Control and Prevention (CDC) to support data collection to better understand CHD prevalence and assess the public health impact of CHD; support the National Heart, Lung, and Blood Institute’s efforts to expand research targeted to the diverse lifelong needs of individuals living with CHD; and join the Congenital Heart Caucus.

CONGRESSIONAL CONGENITAL HEART CAUCUS
The Congressional Congenital Heart Caucus, formed in 2012, continued to grow, reaching more than 20 legislators by 2013’s end. This caucus is an informal group of members of Congress who are dedicated to issues related to congenital heart defects and who serve to educate their constituents and other members on this subject. We are grateful to Congressman Gus Bilirakis, who serves as the founding chairperson of this caucus, as well as Congressman Adam Schiff, who joined as co-chair this year.

CONGENITAL HEART PUBLIC HEALTH CONSORTIUM
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.

ONLINE AND PRINTED MATERIALS
ACHA provides its members with resources for specific congenital heart defects as well as associated medical conditions and common psychosocial issues. Literature such as “Guidelines for the Management of Adults with Congenital Heart Disease” and “Q&A: Tetralogy of Fallot” were added to our growing educational library.

WEBSITE
The ACHA website, www.achaheart.org, serves as the main online portal for information, and there were nearly 135,000 visits to the website in 2013. This included more than 85,000 unique visitors—a 65% increase over 2012—which all told accounted for nearly 344,000 page views.

ACHA DISCUSSION FORUM
A benefit of ACHA membership is the ability to participate in the online Discussion Forum as a means to discuss issues with other members in the ACHA community and to provide and receive support in a moderated and safe environment. There are more than 9,500 topics and nearly 91,000 posts by 8,200 members.

ACHA BLOG
In 2013 we published 125 posts on the ACHA Blog from more than 25 bloggers, which were viewed approximately 47,600 times. ACHA bloggers post on a variety of topics relevant to the CHD community, and included posts such as “Receiving a Transplant: When and If,” “Adult Congenital Heart Disease Myths,” and “The Uncertainty of CHD.”

FACEBOOK PAGE
ACHA continued to use Facebook as a way to inform and interact with the congenital heart disease community. ACHA Facebook membership increased by 56% this year. Visit the ACHA Facebook page at www.facebook.com/AdultCongenitalHeartAssociation.
ACHA TRAVEL DIRECTORY AND PROGRAM DIRECTORY
In collaboration with the International Society of Adult Congenital Heart Disease (ISACHD), ACHA continued to offer a print directory of ACHD services to include 100+ national and international sites capable of providing emergency ACHD care to CHD patients who are traveling. Also in collaboration with ISACHD, ACHA continued to offer an online listing of more than 110 ACHD clinics in the United States and Canada; the directory continues to be the only resource of its kind available in the United States.

ACHA WEBINAR PROGRAM
The ACHA webinar series continues to educate CHD patients and families by presenting webinars on various interesting and timely topics. More than 1,000 individuals attended 13 different webinars in 2013. National experts spoke on topics such as “Understanding Genetic Testing and Hereditary Risk in CHD” and “Life with Single Ventricle: ACHD Patients Living with a Fontan.”

PROVIDER ACTION FOR TREATING CONGENITAL HEARTS (PATCH)
In partnership with the American College of Cardiology (ACC), PATCH aims to engage and educate community and general cardiologists by increasing awareness of the ACC/American Heart Association care guidelines, increasing general cardiologists’ awareness of when referral to an ACHD provider is needed, plus increasing collaboration between ACHD and non-ACHD healthcare providers in order to promote and provide high-quality ACHD care to patients around the country.

HEART-ACHD STUDY
Results of the Health Education and Access Research Trial in Adult Congenital Heart Disease (HEART-ACHD) study,* in collaboration with the Alliance for Adult Research in Congenital Cardiology, show that ACHD patients often have lapses in cardiology care but they were able to improve gaps in knowledge about their heart disease with a simple educational intervention. Subjects also showed a greater understanding of the process of medical research and expressed interest in future research participation. In 2013 these results were published in the Journal of the American College of Cardiology and the International Journal of Cardiology.

FELLOWSHIP
In September, we announced the creation of the ACHA Actelion Fellowship Award to increase the availability of specialized congenital heart care. The fellowship, funded by Actelion Pharmaceuticals US, Inc., will offer training awards to two institutions in the United States with a commitment to high-quality ACHD care. These awards will be used to provide two years of special training for cardiologists wishing to specialize in caring for adults with CHD. The American Board of Medical Specialties recently created a pathway requiring adult CHD specialists to complete several years of adult and pediatric congenital heart training and sit for a subspecialty exam in order to become board certified in Adult Congenital Cardiology.

ACCREDITATION
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 Philadelphia in February to discuss and develop criteria for Level 1 ACHD Programs. Additional work to develop Level 2 criteria began in the latter half of the year, with further delineation to be done in 2014. Accreditation is a process in which individual ACHD programs will undergo careful review to make certain that they provide a standard of quality care to ACHD patients based on published guidelines and standards.

*The project described was supported by Award Number R03HL096135 from the National Heart, Lung, and Blood Institute. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Heart, Lung, and Blood Institute or the National Institutes of Health.

The Congenital Heart Walk continued to bring together thousands of children, adults, and families to unite to fight CHD. More than 50,000 walkers raised more than $1.3 million in 27 locations across the United States from California to Florida and Texas to Minnesota.

The Congenital Heart Walk is an ongoing national effort between ACHA and The Children’s Heart Foundation to raise awareness of the nation’s #1 birth defect, and to support, honor, and remember the millions affected by CHD. To join in our efforts, visit www.congenitalheartwalk.org and unite to fight CHD today!
2013 MEDICAL PROFESSIONAL MEMBERS

JANUARY 1, 2013 to DECEMBER 31, 2013

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 stake in ACHA's mission. The list below includes all paid professional members of ACHA for 2013.

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Farouch Berjis, MD  
Jennifer Binam  
Richard Belin  
Stanley Beder, MD  
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Audrey Beckman  

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JANUARY 1, 2013 to DECEMBER 31, 2013

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Actelion Pharmaceuticals US, Inc.

Gold ($50,000 to $99,999)
Edwards Lifesciences Corporation

Silver ($10,000 to $49,999)
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Anonymous

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Thank you to all of ACHA's donors in 2013. Below is a list of our donors who gave $100 and above.

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*ACHD patient  **CHD family member/spouse

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*ACHD patient  **CHD family member/spouse