

# A Reason for Hope

2011 Annual Report



Hydrocephalus  
Association

# A New Course

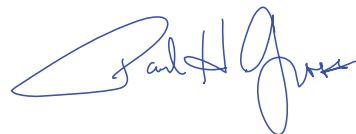
## A Reason for Hope

Hydrocephalus made national headlines in 2011 with the shooting of Congresswoman Gabrielle (Gabby) Giffords on January 8. A few months after the tragic event, Gabby was diagnosed with hydrocephalus and received a ventriculoperitoneal shunt. This invasive surgery made national news, and for the first time the word “hydrocephalus” was being discussed widely in newsrooms across America. I’m saddened that it took a tragedy like this to get hydrocephalus the level of attention it deserves, but I’m hopeful that it will help raise much-needed awareness of the challenges we face. This event was a wake-up call for many and it affirmed the critical need for the Hydrocephalus Association as hydrocephalus has no limits and can alter the life of anyone at any time.

In 2011, the **Hydrocephalus Association** (HA) charted a new course to maximize our impact and position us to experience substantial growth over the next few years. There are currently one million people in America living with hydrocephalus, and for many the HA is one of the only places to turn for support, encouragement and the latest information. This Annual Report details some of our major successes and accomplishments during 2011, and demonstrates why I feel so hopeful about our future. Some major highlights include:

- **New leadership:** We are proud to have secured a highly recognized leader in association management, Dawn Mancuso, MAM, CAE, FASAE, to serve as our chief executive officer. Dawn brings significant association leadership and advocacy experience to the HA and is leading the relocation efforts of our headquarters from San Francisco to Washington, D.C.
- **Commitment to research:** We launched *A Reason for Hope*, a five-year research campaign to focus our efforts on high-yield research strategies that will ensure continued progress in the fight to treat, prevent and cure hydrocephalus. We are proud to have funded two studies to examine cerebrospinal fluid regulation through our Experienced Investigators Program. To date, we have committed \$1.3 million to research.
- **Record year of raising awareness:** Our national HA WALKS raised more than \$1 million in 2011. A record number of 10,000 people participated to show their support and to share about the impact of the condition in communities across America. This is the largest movement in the world representing people affected by hydrocephalus, and it continues to grow each year.

We hope you take pride in the work we were able to accomplish with your support. It is truly only through the contributions and involvement of committed donors, volunteers and members that we are able to carry out our mission. Gabby’s story is one of a *million* reasons why we must continue to fight to advance our cause. We look forward to working together to make a difference in the lives of everyone affected by hydrocephalus.



**Paul H. Gross** *Chairman, Board of Directors*

*“Thank you is such a simple word, but it is said with my whole heart. When my world was falling apart you helped me to understand so much...”*

*– Lucinda Heavenridge,  
Ypsilanti, MI*

# Advances in Research

## A Reason for Hope: Research Plan Launched

In 2011, we unveiled a specific research plan to address the challenges in hydrocephalus research. The plan includes a three-pronged strategy to guide our funding and focus dollars on projects that will yield a high return on investment:

- 1) Stimulate the research ecosystem by continuing to fund collaborative research efforts, such as research conferences, to encourage pilot studies that will ultimately garner funding from the National Institutes of Health and other sources. These efforts will identify promising young scientists and support their mentoring by senior scientists in the field.
- 2) Identify and improve clinical practices, reduce shunting complications and develop consensus in the scientific and clinical community on clinical assessments and outcome measures. We will fund research networks and studies devoted to understanding shunt failure and reducing practice variation.
- 3) Improve the understanding of hydrocephalus etiology to aid in the diagnosis and treatment of the condition and to improve patient quality of life. We plan to devote funding to the identification of biomarkers, the understanding of cerebrospinal fluid regulation and the genetic basis of hydrocephalus. Findings in these areas should enable the discovery of pharmacological interventions, among other possible innovative treatments.

*"I am so thankful that HA exists. I am a 54-year-old woman with NPH that has not responded to shunting... The Association's commitment to research is the only thing that gives me hope for the future." – Katherine Weiser*



*We continue to collaborate with the Hydrocephalus Clinical Research Network (HCRN) to directly impact the state of hydrocephalus treatment and outcomes.*

## HA Grants \$400,000 to Established Investigators

We have now funded grants totaling \$1,367,000 since we initiated our commitment to supporting and funding research in 2009. In 2011, we directly funded \$400,000 to research focused on enhancing our understanding of hydrocephalus. Our 2011 focus explored the dynamics of cerebrospinal fluid (CSF) in the hopes of finding a mechanism to regulate its production or resorption in order to relieve the intracranial pressure that is common with hydrocephalus. The long-term goal of these grants is to create therapeutic interventions—such as a pill—that could control intracranial pressure. Our 2011 grants were awarded to the following investigators:

**Miles Johnston, PhD**, professor of laboratory medicine and pathobiology at the University



of Toronto and senior scientist at the Sunnybrook Research Institute, is investigating cerebrospinal fluid drainage mechanisms, specifically the role that the lymphatic vessels of the brain play in relation to CSF clearance. His group hopes to test how these lymphatic vessels respond to pharmaceutical intervention in relation to CSF drainage.

**Pat McAllister, PhD**, professor of neurosurgery and director of basic hydrocephalus



research at the University of Utah, is investigating abnormal development along the ventricular walls in the brain, which causes blockage of normal cerebrospinal fluid flow. His team hopes to use this information to develop novel approaches to protect or repair a hydrocephalic brain.

## NIH Appoints HA's Chairman to the NINDS Advisory Council



Paul Gross, chairman of the Hydrocephalus Association's board of directors, was one of four new members appointed to the National Advisory Neurological Disorders and Stroke Council, the major advisory panel to the National Institute of Neurological Disorders and Stroke (NINDS). Paul's appointment runs from August 1, 2011, to July 31, 2015. NINDS, one of the institutes under the National Institutes of Health (NIH), is the nation's primary supporter of basic translational and clinical research on the brain and nervous system. In addition to helping NINDS strategically manage its portfolio, the relationships built in this role will help ensure the needs of the hydrocephalus community are heard.



## HA-Sponsored Research Publishes Significant Discovery



Jerold Chun, MD, PhD, a professor at the Scripps Research Institute and its Dorris Neuroscience Center, has discovered a significant factor in the development of hydrocephalus. His findings involve the discovery of abnormally high levels of a lipid called LPA in the brains of mice that develop hydrocephalus. Dr. Chun has shown that prohibiting the buildup of excessive LPA has a preventative effect on the development of hydrocephalus.

Dr. Chun served as the review chair for the HA's 2011 round of research grants focused on cerebrospinal fluid dynamics. He also mentored our postdoctoral fellow, Yun Yung, PhD, who was a grantee from our inaugural Mentored Young Investigators award in 2009 and contributed to these findings around LPA and congenital hydrocephalus. Dr. Chun's findings were published in the September 7, 2011, issue of the journal *Science Translational Medicine*.

## HCRN Partnership Highlight

We are committed to sustaining the research of the Hydrocephalus Clinical Research Network (HCRN) through philanthropic funding. We have started to see the fruit of our partnership to standardize clinical protocol. The first study has already published results reducing postoperative infection rates for shunt surgery by more than 35 percent at the participating centers. HCRN has an effective model for addressing the needs of the pediatric hydrocephalus population, and we seek to extend this model to support the adult hydrocephalus community by supporting clinical research and launching an adult-focused HCRN in the future.



*"Since discovering Teens Take Charge (TTC), I feel more confident about my medical [knowledge]. I know what this is and I know how to handle it. Within the next few weeks, I will be visiting the neurosurgeon for the first time in ten years, and even if I need a revision, I am prepared for what this means because I now have a support group of understanding people through TTC." – Desa Merila, Prescott, WI*

## **Growing Support & Education**

### **Teens Take Charge (TTC)**

We launched Teens Take Charge in 2010 to motivate and empower young people affected by hydrocephalus to advocate, raise awareness and encourage peers. The program teaches teens to become self-advocates both with health professionals and public policy makers, and provides fund raising opportunities and trainings so that teens can be an effective force in making their stories heard. We were able to dedicate a staff member to coordinate the program and grow our social media presence to reach more youth who have been diagnosed with or affected by hydrocephalus. As a result, TTC connected more than 800 teens through social media in 2011. Members have hosted awareness days at their schools and participated in advocacy efforts by carrying their message, both in person and via letter, to representatives on Capitol Hill. In addition, the group secured a \$50,000 grant from the Medtronic Foundation to continue their support and advocacy work in 2012.



### **Support Groups Host Local Awareness Programs**

Conference on Hydrocephalus  
*St. Louis, MO*

Gillette Children's Hospital  
Conference on Hydrocephalus  
*Minneapolis, MN*

NBC's Health and Wellness Fair  
*Hartford, CT*

Chico High School  
*Chico, CA*

Senior Citizen Health Fair  
*Westchester, NY*

### **Support Groups Reach New Communities**

We are committed to ensuring that individuals affected by hydrocephalus have a place to turn for support and encouragement. We continue to partner with local hospitals to launch new support groups and programs across the nation. In 2011, support groups were formed in the following communities: Birmingham, AL; Tucson, AZ; Chico, CA; Fresno, CA; Hartford, CT; Washington, DC; Miami, FL; Orlando, FL; Minnesota, MN; Twin Cities, MN; Charlotte, NC; Philadelphia, PA; Nashville, TN. The groups hosted 69 gatherings in 2011 plus several community events to raise awareness. We strive to offer support groups within reach for anyone diagnosed with hydrocephalus and will continue to recruit volunteers to meet this goal. To view our complete and ever-growing list of support groups, please visit our website at [www.hydroassoc.org](http://www.hydroassoc.org).

### **Scholarship Awards**

The year 2011 marked our 17th year of awarding educational scholarships to students who have hydrocephalus. Despite the challenges and obstacles they face, these future leaders of our community are able to further their education, help their community and inspire their peers. We were pleased to provide nine scholarships, thanks to the support of the following endowed scholarship funds: Gerard Swartz Fudge Memorial Scholarship Fund, Morris L. and Rebecca Ziskind Memorial Scholarship Fund, Anthony Abbene Scholarship Fund, the Justin Scot Alston Memorial Scholarship Fund, the Mario J. Tocco Hydrocephalus Foundation Scholarship Fund and the Giavana Marie Melomo Memorial Scholarship Fund.



## Increased Awareness & Fund Raising

### A Million Reasons to Walk!

The year 2011 was a spectacular year for HA WALKs and special events, which raised over \$1 million thanks to our loyal and very determined volunteer WALK chairs and all the volunteers who work tirelessly to raise money to further our mission. The HA WALK program started in 1983 with a small group of families walking across the Bay Bridge in San Francisco. Today, HA Walks mobilize 10,000 individuals and are held in communities across the nation. The events have become more than just a series of walks — they are a time of celebration for those who have triumphed over difficult health issues and a time of reflection and remembrance for those we have lost along the way. We are proud of what we have accomplished and will continue to utilize events like HA WALKS as a catalyst for reaching more people in need and for raising critical support and awareness for our research, advocacy and education efforts.

### Kids to Cure Hydrocephalus

A new fund raising/education program was introduced in the fall of 2011, *Kids to Cure Hydrocephalus*. Raising \$4,100 from 110 student participants, *Kids to Cure Hydrocephalus* — a combined public education and fund raising initiative for schools — was led by veteran Long Island WALK Chair, Mia Padron. Mia's 10-year-old son, Tyler, lives with the challenges of hydrocephalus, and Mia wanted to increase his peers' knowledge about the condition. With a representative from a shunt manufacturing company at her side (who brought brain models and shunts to pass around as visual aids), Mia spoke to each class in Tyler's school. Tyler willingly led a question-and-answer session about his condition and shunt. By the end of this event, several hundred children had learned about hydrocephalus and shared what they learned with family and friends. The evening after speaking to the classes, Mia received numerous phone calls from parents telling her their son or daughter had told them "all about hydrocephalus," relating Tyler's experience.

## WALK AND SPECIAL EVENT AWARDS

### 2011 HA WALK Award Winners

#### Participant Growth

(Increase over Previous Year  
– Number of Walkers)

- 2011 Birmingham, AL WALK
- 2011 South Florida WALK
- 2011 St. Louis, MO WALK
- 2011 Salt Lake City, UT WALK

#### Revenue Growth

(Increase over Previous Year  
– WALK Revenue)

- 2011 Long Island, NY WALK
- 2011 Salt Lake City, UT WALK

#### Revenue Over Budgeted Goal

- 2011 Denver, CO WALK

#### Most Cost Effective WALK

(Lowest Expense Ratio)

- 2011 Cambridge, MA WALK

#### Overall WALK Revenue

- 2011 Long Island, NY WALK
- 2011 Denver, CO WALK
- 2011 Chattanooga, TN

#### Best First Year WALKS

- 2011 Seattle, WA WALK
- 2011 Middlebury, CT WALK

#### HA Pacesetter Award

- San Francisco, CA WALK

#### Walk Chair of the Year

Mia Padron  
(Long Island, NY)

### 2011 SPECIAL EVENTS AWARDS

#### #1 Revenue Over Goal Winner:

National Capital 5K Run/WALK  
(Washington, DC)

#### Best First-Year Special Events

National Capital 5K Run/WALK  
(Washington, DC)

Snow Shoe WALK  
(Steamboat Springs, CO)



## Team Hydro Swims with the Sharks!

For the fourth year, the Hydrocephalus Association was the beneficiary of Team Hydro's participation in the annual San Francisco Sharkfest. This year's event broke all previous Team Hydro records, raising an astounding \$114,000, resulting in funding, for the second consecutive year, to support the Team Hydro/Kate Finlayson Research Grant. Team Hydro is a group of open-water swimmers who swim from Alcatraz to Aquatic Park through the icy-cold, shark-infested waters of San Francisco Bay. Team Hydro was founded in 2008 by brothers Peter and Sam Finlayson in honor of their sister, Kate, who lived with the challenges of hydrocephalus. Sadly, Kate passed away in November 2010, at the age of 26, from a shunt infection. This important research grant named in her memory keeps her spirit alive and continues the fight against hydrocephalus.



*Kate Finlayson*  
11/16/84 - 11/27/10

## Community Events Grow to Support the HA

Every year, we are extremely fortunate that many volunteers across the United States initiate and coordinate fund raising events in their own communities. The growing number of local events demonstrates the impact and importance of our programs and services. Events held in 2011 included: the DUH Event, a high-end auto show in Denver; MX for Children, a multiple-city motocross event led by volunteer Paul Gross; Extreme Athletes, who run for hydrocephalus in marathons across the country; Hydro Benefit Concert coordinated by Pam and Mark Meabon in Dillsburg, PA; Lehigh Acres High School year-round student fund raisers in Florida; the St. Lothar Golf Tournament in Pennsylvania, coordinated by Eric and Sara Zelesky; and now in its 14th year, the Thanks for Running 5K held on Thanksgiving Day morning, organized by Amy Maynard from Fitchburg, MA. We salute all of our dedicated volunteers who work creatively to raise money to help fund our mission.







## Advocacy in Action

### Advocating for Change

Our advocacy strategy spans a broad range of activities — from local grassroots awareness efforts such as our WALK program to state-level efforts to establish hydrocephalus awareness days/months to our federal efforts, which focus on research programs at the NIH and other legislative initiatives within the U.S. Congress. Our primary advocacy goal is to ensure that the federal government is investing adequate resources to accomplish the following:

- To understand the breadth and depth of the impact of hydrocephalus;
- To make funding hydrocephalus research for improved treatments and cures a high priority;
- To support those affected with hydrocephalus with appropriate programs.

### Caucus Briefing on Capitol Hill

In partnership with the Pediatric Hydrocephalus Foundation and other organizations, we participated in a briefing for the Congressional Hydrocephalus Caucus on Capitol Hill. The goal was to educate legislators and their staffs about the need to devote more resources to hydrocephalus research. The day began with a meeting with the staff of the Armed Services Committee to explore the funding opportunities for hydrocephalus in the Congressionally Directed Medical Research Program and the defense appropriations for traumatic brain injury. Next, the delegation participated in a briefing for the Congressional Hydrocephalus Caucus, with a great set of speakers, from patients and advocates to medical professionals including neurologists, neurosurgeons and a neuropsychologist. We ended the day meeting with Representative Rosa DeLauro's staff, the Energy and Commerce Committee staff and the minority speaker's staff. The meetings gave us hope, as Representatives immediately connected with the mission of the organization and suggested several action steps for us to pursue. A broader set of efforts are planned for 2012 as we transition to our new headquarters in Washington, D.C.

# 2011 Donor List

Thank you for your loyal support  
to the hydrocephalus community.

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Cathy Fox  
Scott Fox  
Drew Camden Geloni  
Mariana Gladney  
Amy Glover  
Katie Goldman  
Paul Gross  
William Gross  
Willa Maye Harple  
Parker Hendrix  
Dale and Tammy Hoch  
Benjamin Hodges  
Brendan Horak  
Tommy Howells  
Justin Hunter

Justin Hunter and  
Goddaughter Charlotte  
Cooper Inskip  
Ryan K. James  
Daniel Jones  
Dylan Jouppi  
Glenn Karahadian  
Sofia Karch  
Patrick Keller  
Ralph Kistler  
Cate Kolbash's daughter  
Eva Kluter Kruse  
Jilliam Kuntz  
Emma Lane  
Dean Laubach  
Elijah Lawrence  
Emily Lawrence  
Max Lehnert  
Mia McIntosh and  
Jonah Leonhardt  
Audrey Lintott  
Samuel Loewenstein  
Mady & Rudy  
Isabella Mallozzi  
Dawn Mancuso  
Elyse Mandel  
Sam Marks  
Patrick Martinage  
Martha Mason  
Maddy Matteucci  
Jack May  
Mary Madison McCarley  
Flynn McCracken  
Mia McIntosh  
Parke McLellan  
John McNulty  
Evan Miles  
Grant Miller  
Jameson Miller  
Daniella Mindt  
Addox Morrow  
Mason Munch  
Sara Nieves  
Ian Noble  
Bekka Noelle  
Lisa Norton  
Stephanie Norton  
Madelyn Nunez  
Barrett O'Connor  
Rebecca Osgood  
Katie Panasko

Thomas Penman  
Brent Ryan Pierce  
Evan Plucker  
Ashlyn M. Powell  
Wolfgang Priebe  
Mikayla Rabick  
Joey Ragazzo  
Siobhan Reardon  
Arnold and Arlene Reifer  
Cindy Reyes  
Everett Riser  
Mary Roach  
Emily Rogers  
Grace Rosanova  
Eliana Russo  
Keenan Ryder  
Dr. Steven Schneider  
Joseph Schwab  
Aryeh Zaid Ben Shoshana  
Zachariah Smith  
Alivia Spaulding  
Sally Spicer  
Joysan Steffy  
Joshua Stein  
Brody Sticha  
Elliot Carns Straw  
Haarlan Swanson  
Rita Swedroe  
Tracy Taback  
Jacob Talbert  
Dara Tannariello  
Logan X. Texidor  
Those with NPH  
Cameron Toone  
Austin Wagner  
Cory Walker  
Cameron Walters  
Susan Wason  
Chad Whisenant  
Catherine Williams  
Haley Williams  
Kasey Williams  
Stephen Williams  
Karen Wilson  
Martha Wilson  
Lev Yudovich  
Ali M Yusuf  
Quinten Zalesky  
Nora Zehrung





## In Memory Of

Shirley B. Adams  
Gladys Adler  
Lillian and Henri Adrien  
Everett B. Andrews  
Tim Arnett  
Annie Mae Baker  
David J. Burnham Sr.  
Anne Caprera  
Christina Cavanaugh  
Akhil Chandra  
Tyler Chardavoyne  
Louis Christopher  
Doris Conrad  
Eileen Cook  
Bob Crawford  
Isaac Crites  
Bill Crownover  
Leonard Cruth  
Ruthann Davenport  
Mary Louise Duffy  
Anna Marie Ellsworth  
Kate Finlayson

Gerard Fudge  
Gloria Ann Gentile  
Jack and Janet Gorter  
Salomon Hakim, MD, PhD  
Trisha L. Hammond  
Ernest Harris  
Edgar Herring  
Kenneth C. Hertz, MD  
Jim Hill  
John P. Hulka  
Aldon Ingersoll  
Pia Johansson  
Anthony Jason Keller  
Todd E. Kendrick  
Shirley Kenyon  
Janet Kondrk  
Hal Lahey  
Brian Lentill  
Aunt Martha  
Matthew McCormack  
Barbara McGee

Christian Molica  
Gregory L. Munoz  
Dan Alan Naylor  
Brian Christopher Newcomer  
Charlie & Doris O'Connor  
Susan K. Pendarvis  
Liam Jon Robbins  
Genevieve Sachs  
Cecelia Sawicki  
Randy Smith  
Wendell Sowby  
Jenna Steenwyk  
Guadalupe Taskiran  
Bobbie J Tomlinson  
Joan L. Venes, MD  
Linda Rose Ward  
Richard Austing West  
William Wiggins  
Danelle Williams  
John Yaroma  
Marissa Joy Young

# 2011 Audited Financial Statement

## Statement of Financial Position

At December 31, 2011

### ASSETS

#### Current Assets:

Cash and cash equivalents	\$499,741
Grants receivable within one year	200,000
Pledges receivable within one year	13,500
Accounts receivable	1,544
Investment in low duration bond fund	348,019
Prepaid expenses	26,185
Inventory	10,680

**Total Current Assets \$1,099,669**

Permanently restricted investment in low duration bond fund	80,818
Pledged receivable in 2013	1,500
Property and equipment net of accumulated depreciation	28,498
Deposits	5,006

**Total Assets \$1,215,491**

### LIABILITIES

#### Current Liabilities:

Accounts payable and accrued expenses	\$121,773
Lease payable, current	4,480
<b>Total Current Liabilities</b>	<b>126,253</b>

#### Long term Liabilities:

Lease payable, non-current	16,842
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**Total Liabilities \$143,095**

### NET ASSETS

Unrestricted net assets	\$743,927
Temporarily restricted net assets	247,651
Permanently restricted net assets	80,818

**Total Net Assets 1,072,396**

**Total Net Assets and Liabilities \$1,215,491**

## Statement of Activities

For the year ended December 31, 2011

### SUPPORT AND REVENUE

Restricted grants and donations	\$370,722
Unrestricted contributions	395,364
Fundraising (\$923,818 revenues less \$112,523 expenses)	811,295
Sale of books, publications and other items	20,281
Interest and dividends	11,892
Net investment gain (loss)	(2,490)
Other income	3,225

**Total Support and Revenue \$1,610,289**

### EXPENSES

Research	608,149
Public support and education	462,742
Advocacy	84,610
Hydrocephalus conference	19,855

**Total Program Expenses \$1,175,356**

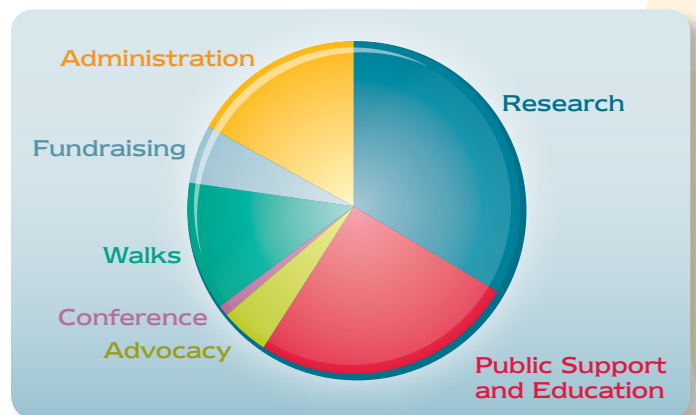
Walks	226,047
Fund Development	102,793
Administration	308,418

**Total Expenses \$1,812,614**

Change in net assets (202,325)

Net assets at beginning of period 1,274,721

**Net assets at End of period \$1,072,396**





### Officers of the Board

Paul Gross, *Chairman*  
Raymond R. Moser, Jr.,  
*Senior Vice Chairman*  
Barrett O'Connor, *Vice Chairwoman*  
Curt Stewart, *Secretary*  
Craig Brown, *Treasurer*

### Directors

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Debby Buffa  
Aseem Chandra  
Russell G. Fudge  
Ralph A. Kistler  
Robert Kondrk  
Matt Kursh  
Deborah Phillips  
Marc Randolph  
Mike Schwab  
Marvin L. Sussman, PhD  
Marion L. Walker, MD

### 2011 Staff

Dawn Mancuso, MAM, CAE, FASAE,  
*Chief Executive Officer*  
Jerry Acosta, *Operations Manager*  
Jennifer Bechard, *Support Group Liaison*  
Randi H. Corey, *Director of Special Events*  
Jordan Faigen, *Campaigns Manager*  
Pip Marks, *Support and Education Director*  
Neena Narayanan, *Database Coordinator*  
Gavin Reed, MPH, *Research Associate*  
Karima Roumila, MPH,  
*Community Programs Director*  
Rick Smith, *Transition Team, Interim CEO*  
Thomas G. Smith,  
*Adult Services & Outreach Coordinator*

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Richard D. Ellenbogen, MD  
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Bruce A. Kaufman, MD  
John R. W. Kestle, MD  
Mark Luciano, MD  
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J. P. (Pat) McAllister II, PhD  
J. Gordon McComb, MD  
C. Scott McLanahan, MD  
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Harold L. Rekate, MD  
Jeffrey H. Wiscoff, MD  
Marion L. Walker, MD  
Michael A. Williams, MD



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