



The CFIDS Association of America

2013

Annual

Report

Participatory Research



Predictive Measures



Personalized Treatments



## Advancing Science: A Case for Hope, A Look Ahead

In 2013 there were immense challenges in the ME/CFS landscape and a number of changes at the CFIDS Association. Through it all there is much to celebrate, hope for an even brighter future and an exciting path laid out ahead.

With the departure of 22 year leader, [Kim K McCleary](#), the Association welcomed our [new president and CEO, Carol Head](#), to the helm in October. Along with her management experience and entrepreneurial drive, Carol has brought a renewed sense of urgency and focus to the fight to solve ME/CFS. She is leading our efforts to work with patients, researchers, funders, and government agencies to drive forward our work to eradicate this debilitating illness.

### Advancing Science with Our Research Institute Without Walls

The Solve ME/CFS Initiative has worked over the past 5 years to invest your donations in our Research Institute Without Walls (RIWW). Our innovative RIWW continues to provide early funding to the most promising researchers, using our [SolveCFS BioBank](#) to put patients at the center of that research; pairing patient samples and clinical information with the brightest investigators from the best medical institutions in the world.

The Research Institute Without Walls focuses on:

Priority Area	Research Investment
Identifying disease subtypes and biomarkers	45%
Developing disease-modifying treatments	25%
Defining ME/CFS	20%
Software tools	10%

#### Identifying disease subtypes and biomarkers

ME/CFS is a multifaceted and complex disease. To discover the cause and effective treatments we must break down the complexity and identify groups of patients that are similar to one another. How is that done? With blood and clinical information. Blood is a 'molecular biopsy' that can provide clues to biology from all parts of the body. **The SolveCFS BioBank harnesses the power of your information and your sample and puts You at the center of research.** The BioBank has attracted some of the brightest investigators from the best medical institutions including Harvard, Columbia, Johns Hopkins, University of Alberta, NYU Langone Medical Center and University of Toronto.

#### Developing Disease-modifying treatment

While funding cutting edge research to identify a cause, we are also identifying treatments that can help restore function and alleviate symptoms of ME/CFS. While we work towards a cure we must develop disease-modifying treatments. As an example, in 2012, the Solve ME/CFS Initiative, together with BioVista, succeeded in identifying a new drug combination therapy in 11 months – an unprecedented success story in drug discovery. The combination therapy targets major symptoms of ME/CFS including fatigue, pain and sleep disturbance. We are now working with the FDA to design a clinical trial to test this novel therapy in ME/CFS patients with the aim of starting the trial in 2014. We anticipate being the first to market with an FDA-approved drug for ME/CFS. **Not only will this dramatically help patients but it will change the face of ME/CFS forever** – just as Lyrica did for Fibromyalgia.

## Defining ME/CFS

Diseases must be clearly and unambiguously defined so that causes, and the cures can be discovered. We have partnered with Lenny Jason of DePaul University to use the data from the SolveCFS BioBank to help refine how ME/CFS is defined. This research will help identify the “core signs and symptoms” of ME/CFS so that the disease can be measured the same way by all investigators.

The Solve ME/CFS Initiative is working on a partnership with a real-time online platform where people can connect with fellow patients and expand our capacity for patient centered outcomes research through their shared data. The data can help researchers better understand the nature of the illness, detect patterns, and develop more effective therapies. Partnering, combining and growing our community, we will create a big data set of “well-defined and reliable” patient-reported outcome measures to provide evidence of treatment benefit. Managing, understanding and using this kind of big ME/CFS data will be key to innovating the effective treatment for ME/CFS patients.

## Software tools

We have partnered with a biotech company to build a digital library – one centralized knowledge base – of all the ME/CFS medical literature and all open source biological data sets. This digital library brings the information to one place and translates it into a standard form. Software is under development to integrate this knowledge in order to generate theories that can lead to therapies.

[Learn more about all of progress underway through the SolveCFS BioBank in a 2013 issue of the SolveCFS chronicle, beginning on page 3. Read MORE](#)

## Other Important Areas of Investment

### Helping Your Voice be Heard on a Federal Level

The Solve ME/CFS Initiative is focused on efforts to fund and conduct research leading to improved methods of diagnosis and treatment of ME/CFS. We recognize the importance of the federal government for two key reasons. First, FDA is responsible for approving all drugs and medical devices for use in the US. And second, federal recognition of the public health impact and burden of ME/CFS and pro-actively stepping up to its role in protecting the health of Americans is important to successfully defeating this illness. We can disagree at times with how it is wielded, but we cannot ignore that power.

In a recent blog post – [Hope on the Hill – ME/CFS in Washington DC](#) – we reviewed the roles of the various offices and agencies within the government. While the federal government historically has a perceived lack of urgency in issues related to ME/CFS, we have seen specific evidence that ME/CFS is on the federal radar. [In our post we lay out](#) tangible, specific activity – including the appointment of the IOM committee to develop clinical diagnostic criteria – that we feel indicates an important opportunity to build an emboldened base of federal support, opening the door to validation, funding and research.

[Read More HERE](#)

## Connecting with Patients, Fueling Research Involvement

We know that we can't achieve our goals without an informed and connected patient population. You are a key ingredient to making ME/CFS understood, diagnosable and treatable. To that end, we are working to empower patients with more information through our Catalyst Cafés, [e-newsletters](#), the [SolveCFS Chronicle publication](#) and online.

More than a quarter of a million people visited the CFIDS Association website last year, most searching for answers, looking for hope. The Association holds the most extensive library of patient information and resources, brings the latest updates and research opportunities to your fingertips and helps patients feel less alone. In an effort to make this information easier to find, readily share-able and more deeply engaging we have launched a new web presence which replaces the SolveCFS BioBank micro-site, CFIDS.org and the Research1st blog with one synthesized online presence. The synergy achieved through [www.SolveCFS.org](http://www.SolveCFS.org) will reach more patients, engage more in the research process and better involve all ME/CFS stakeholders in the important work of the Association. In fact, early numbers tell us that people are staying on the site more than twice as long as they did on the old website – a key indicator that visitors are finding what they need in a more welcoming format.

We continue to hold Catalyst Café events across the US. Meeting in homes and offices, restaurants and community rooms, Association staff members are bringing details about our research program and its impact to people like you. *"I think it is awesome that you actually get out and meet the people who are actually sick, who you are trying to help."* [Anna Zapp, Lafayette, Colorado](#). Anna was so moved by her Catalyst Café experience that she was inspired to [write a blog post](#) about her life and her renewed hope.



*You can help us make a difference in the lives of all those facing the daily struggles of life with ME/CFS. Please join other ME/CFS patients and their loved ones in making a donation today to continue our important work.*

***We can solve this together.***

**THE CFIDS ASSOCIATION OF AMERICA, INC.**  
**STATEMENT OF FINANCIAL POSITION**

*DECEMBER 31, 2013*

(WITH COMPARATIVE TOTALS FOR DECEMBER 31, 2012)

	December 31, 2013			Totals	December 31, 2012
	Unrestricted	Temporarily Restricted	Permanently Restricted		
<b>ASSETS</b>					
Current Assets					
Cash and cash equivalents	\$ 1,144,155	\$ 300,048	\$ -	\$ 1,444,203	\$ 972,541
Contributions receivable, net	314,837	-	-	314,837	11,473
Other receivables	1,198	-	-	1,198	937
Inventories	359	-	-	359	515
Prepaid expenses	5,543	-	-	5,543	8,012
<b>Total Current Assets</b>	<b>1,466,092</b>	<b>300,048</b>	<b>-</b>	<b>1,766,140</b>	<b>993,478</b>
Property and Equipment					
Office furniture and fixtures	35,240	-	-	35,240	77,292
Computers and related equipment	37,197	-	-	37,197	69,806
Leasehold improvements	-	-	-	-	29,259
	72,437	-	-	72,437	176,357
Less accumulated depreciation	(61,882)	-	-	(61,882)	(159,390)
<b>Net Property and Equipment</b>	<b>10,755</b>	<b>-</b>	<b>-</b>	<b>10,755</b>	<b>16,967</b>
Other Assets:					
Beneficial interest in assets held by others	-	9,885	5,400	15,285	13,346
Accumulated policy value of life insurance	-	11,612	-	11,612	12,500
<b>Total Other Assets</b>	<b>-</b>	<b>21,477</b>	<b>5,400</b>	<b>26,877</b>	<b>25,846</b>
<b>Total Assets</b>	<b>\$ 1,476,847</b>	<b>\$ 321,525</b>	<b>\$ 5,400</b>	<b>\$ 1,803,772</b>	<b>\$ 1,036,291</b>
<b>LIABILITIES AND NET ASSETS</b>					
Current Liabilities:					
Accounts payable	\$ 13,502	\$ -	\$ -	\$ 13,502	\$ 52,412
Accrued payroll expenses	28,022	-	-	28,022	23,436
Deferred revenue	-	-	-	-	3,162
Capital lease obligation - current	4,619	-	-	4,619	4,102
<b>Total Current Liabilities</b>	<b>46,143</b>	<b>-</b>	<b>-</b>	<b>46,143</b>	<b>83,112</b>
Other Liabilities:					
Capital lease obligation - noncurrent	12,637	-	-	12,637	17,256
<b>Total Liabilities</b>	<b>58,780</b>	<b>-</b>	<b>-</b>	<b>58,780</b>	<b>100,368</b>
Net Assets					
Unrestricted					
Undesignated	1,232,127	-	-	1,232,127	620,705
Board designated	185,940	-	-	185,940	185,831
<b>Total unrestricted</b>	<b>1,418,067</b>	<b>-</b>	<b>-</b>	<b>1,418,067</b>	<b>806,536</b>
Temporarily restricted	-	321,525	-	321,525	123,987
Permanently restricted	-	-	5,400	5,400	5,400
<b>Total Net Assets</b>	<b>1,418,067</b>	<b>321,525</b>	<b>5,400</b>	<b>1,744,992</b>	<b>935,923</b>
<b>Total Liabilities and Net Assets</b>	<b>\$ 1,476,847</b>	<b>\$ 321,525</b>	<b>\$ 5,400</b>	<b>\$ 1,803,772</b>	<b>\$ 1,036,291</b>

**THE CFIDS ASSOCIATION OF AMERICA, INC.**  
**STATEMENT OF ACTIVITIES**

*YEAR ENDED DECEMBER 31, 2013*

(WITH COMPARATIVE TOTALS FOR YEAR ENDED DECEMBER 31, 2012)

	Year Ended December 31, 2013			Totals	Year Ended December 31, 2012
	Unrestricted	Temporarily Restricted	Permanently Restricted		
Support and revenues:					
Public support:					
Contributions and grants	\$ 1,688,329	\$ 573,037	\$ -	\$ 2,261,366	\$ 1,088,346
Revenues:					
Research subcontracts	18,091	-	-	18,091	12,357
Educational material sales	-	-	-	-	851
Interest and other	2,432	-	-	2,432	2,615
	20,523	-	-	20,523	15,823
Net assets released from restrictions	375,499	(375,499)	-	-	-
Total support and revenues	2,084,351	197,538	-	2,281,889	1,104,169
Expenses:					
Program services:					
Research	916,340	-	-	916,340	868,414
Engagement	248,936	-	-	248,936	189,854
Supporting services:					
Management and general	68,768	-	-	68,768	45,201
Fundraising and development	236,808	-	-	236,808	144,667
Total expenses	1,470,852	-	-	1,470,852	1,248,136
Loss on disposal of assets	1,968	-	-	1,968	-
Change in net assets	611,531	197,538	-	809,069	(143,967)
Net assets, beginning of year	806,536	123,987	5,400	935,923	1,079,890
Net assets, end of year	\$ 1,418,067	\$ 321,525	\$ 5,400	\$ 1,744,992	\$ 935,923

**THE CFIDS ASSOCIATION OF AMERICA, INC.**  
**STATEMENT OF FUNCTIONAL EXPENSES**

YEAR ENDED DECEMBER 31, 2013

(WITH COMPARATIVE TOTALS FOR YEAR ENDED DECEMBER 31, 2012)

	Year Ended December 31, 2013					Year Ended December 31, 2012
	Program Services		Supporting Services		Totals	
	Research	Engagement	Management and General	Fundraising and Development		
Contract services	\$ 130,573	\$ 133,828	\$ 15,614	\$ 74,475	\$ 354,490	\$ 175,623
Salaries and benefits	355,841	70,375	37,663	88,108	551,987	536,972
Payroll taxes	23,751	8,318	4,452	10,414	46,935	41,273
Direct grants	208,700	-	-	-	208,700	235,121
Printing and postage	1,561	8,921	175	12,846	23,503	21,647
Repairs and maintenance	638	223	120	280	1,261	2,068
Supplies	3,001	982	526	1,615	6,124	3,392
Educational materials/ cost of sales	-	157	-	-	157	279
Travel expenses	24,539	4,944	1,606	23,634	54,723	74,164
Event expenses	66,638	-	-	2,922	69,560	17,880
SolveCFS BioBank Costs	52,999	-	-	-	52,999	24,481
Insurance	4,106	1,438	770	1,801	8,115	7,451
Telephone	1,853	1,619	267	2,341	6,080	6,222
Occupancy costs	25,124	8,799	4,709	11,016	49,648	65,352
Depreciation	4,477	1,568	839	1,963	8,847	13,192
Miscellaneous	12,539	7,764	2,027	5,393	27,723	23,219
<b>Total program and supporting services expenses</b>	<b>\$ 916,340</b>	<b>\$ 248,936</b>	<b>\$ 68,768</b>	<b>\$ 236,808</b>	<b>\$ 1,470,852</b>	<b>\$ 1,248,136</b>
Management and general expenses					\$ 68,768	\$ 45,201
Fundraising and development expenses					236,808	144,667
<b>Total management and general, and fundraising and development expenses</b>					<b>\$ 305,576</b>	<b>\$ 189,868</b>
<b>Total support and revenue</b>					<b>\$ 2,281,889</b>	<b>\$ 1,104,169</b>
Supporting services ratio					13.39%	17.20%

[www.SolveCFS.org](http://www.SolveCFS.org)

