

**CURE**  
Citizens United for Research in  
**EPILEPSY**



# Hope, Innovation, Discovery



2014 ANNUAL REPORT



“You just call out my name  
And you know wherever I am  
I’ll come running to see you again  
Winter, Spring, Summer or Fall  
All you got to do is call  
And I’ll be there, Yes I will  
**You’ve Got a Friend”**

—

Carole King

1971



# Welcome & Thank You

Our 2014 Boston headliner, Carole King, summed up the year perfectly in her song “You’ve Got A Friend.” We continue to be moved by the involvement and encouragement of so many gifted and talented people. They have in many cases “come running” to help, even when not called. The participation and generosity of these believers and kindred spirits on our journey of hope, innovation and discovery are what help us push ahead toward the cure for epilepsy.

2014 marked the advent of our stewardship of the Epilepsy Genetics Initiative, a signature program of CURE. In partnership with several other organizations, medical centers and institutions, this initiative enables us to capitalize on each other’s strengths and resources – removing the barriers that impede data-sharing among researchers, and bridging the gap between people with epilepsy, clinicians and researchers to advance precision medicine in epilepsy.

And we looked inward in 2014 to qualify and quantify our own efforts based on the research findings of Benenson Strategy Group, in fundraising and in raising awareness of epilepsy. We also worked with Deutsch, Inc. to help us refine our mission and better communicate our vision to our constituents and the public at large.

As we look back, we cannot help but be struck by what a remarkable year it was for all of us at CURE.



We are truly grateful for the  
participation and generosity of these believers  
and kindred spirits on our journey of  
**hope, innovation and discovery.**







Our mission is to

# CURE EPILEPSY,

TRANSFORMING & SAVING MILLIONS OF LIVES.

We identify and fund cutting-edge research, challenging scientists worldwide to collaborate and innovate in pursuit of this goal.  
Our commitment is unrelenting.





Each individual in this report—from patients and loved ones, to researchers—shares our core belief that uniting around the common goal of finding cures for the epilepsies will lead us to the day when we can deepen our understanding of epilepsy and, ultimately, **defeat it.**



# Impact

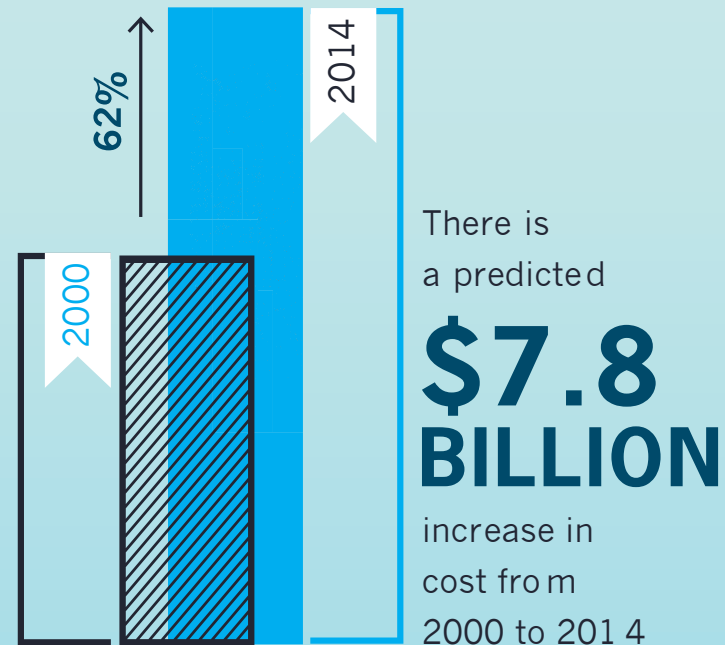
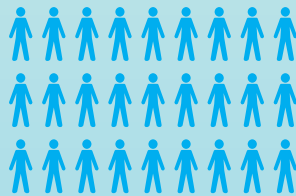
# Cost of Epilepsy & Economic Burden Statistics

Last study done on cost of epilepsy in the US was in 2000.



**200000**  
NEW CASES  
of epilepsy per year in US

There are **2.7**  
**MILLION**  
cases of epilepsy in the US  $\times 100,000$



The lifetime cost of epilepsy for an estimated 181,000 people with onset in 1995 is projected at \$11.1 billion, and the annual cost for the estimated 2.3 million prevalent cases is estimated at \$12.5 billion. Indirect costs account for 85% of the total and, with direct costs, are concentrated in people with intractable epilepsy.

In 2000, \$12.5 billion was the annual cost for 2.3 million cases.

If you believe in adjusting for inflation then, in 2014, 2.7 million people in the US with epilepsy will cost \$20.3 billion per year in direct and indirect costs for epilepsy.



# We Have CURE Grantees All Over the World

Since 1998, CURE has invested \$34 million in more than 190 cutting-edge research projects in 15 countries.



We challenge scientists to collaborate and innovate in pursuit of our goal to **CURE EPILEPSY**

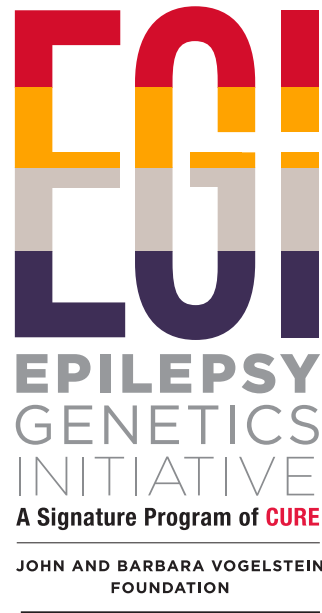


**“I want epilepsy dead.  
I want it decoded and destroyed.  
And CURE's the best chance we've got.”**

—

**Evelyn Nussenbaum**  
**BOARD MEMBER, CURE**





# Epilepsy Genetics Initiative

A Signature Program of CURE

Genetics **research** and the application of **precision medicine** are reaching beyond what was thought possible just a few years ago in the **discovery**, diagnosis and treatment of a wide range of epilepsies. The broad collection of patient exome data from organizations, clinicians, scientists and researchers has until now largely been gathered and stored by those groups in silos. Today, the Epilepsy Genetics Initiative is changing that – creating a centralized database to hold the genetic data of people with epilepsy, and giving access to researchers to analyze and re-analyze the data until the cause of a person's epilepsy can be found.

Our stewardship of this game-changing initiative is possible only through the generous support of The John & Barbara Vogelstein Foundation. The foundation and family behind it are more than this initiative's principal sponsors: they are a part of the CURE family, helping us to advance epilepsy research and to find answers for patients.



“EGI will help to ensure that every patient benefits from the remarkable advances in epilepsy genetics and the emerging paradigm of targeting treatments to the exact underlying causes of epilepsy.”



Dr. David B. Goldstein

DIRECTOR OF THE INSTITUTE OF GENOMIC MEDICINE  
AT COLUMBIA UNIVERSITY MEDICAL CENTER







## Stories that Touched Us

At CURE we are fortunate to hear hundreds of stories of people getting involved to help us every year. We are amazed by them. We are humbled by them. This year we've chosen to highlight four stories that tell the CURE story through the hearts and minds of some of these incredible people and organizations.

omtom

RAGNAR  
WASHING



“We’re helping frame the discussion around a topic that can save lives, eliminate the suffering of patients and their families and one day find a cure for epilepsy. We’re proud of the results and our involvement with CURE.”

—

Danny Franklin

**BENENSON STRATEGY GROUP**





## BSG & Deutsch

### Corporate 'in kind kindness'

At no time in our history did we have the luxury to conduct market research at the level we did in Fall 2013, nor did we have the dedicated and passionate expertise to analyze that data for organizational and donor insights that would strengthen our ability to communicate more effectively with our constituents. The generous in-kind support of two globally recognized firms, Benenson Strategy Group (BSG) and Deutsch, made this possible. When they came to know our story, they stepped forward to help.

It all began, as it often does here at CURE, with one person telling our story to another. In this case that other person happened to be Donny Deutsch, renowned branding expert, television host and Chairman of Deutsch Inc., one of the nation's largest branding and advertising agencies. And, as is also often the case, he was surprised to learn how many people are impacted by epilepsy and how little it is part of the public conversation. So he brought the CURE challenge to his team in an unprecedented first step, helping us look at our brand holistically, including our mission, vision and communications strategy.

Tyler Helms, Senior Vice President, Group Account Director at Deutsch, explained: "We have a lot of requests to do pro bono work, but Donny felt CURE was different. Different because epilepsy impacts so many families. Different because, unlike other diseases that seem to have almost universal understanding, epilepsy seems to be largely misunderstood and out of mind of the general public." And Tyler added, "after we began working with CURE we had a lot of questions around the behaviors, motivations and perceptions of those that give, seek information about and are impacted by epilepsy. Deutsch is a data driven communications agency, we want, need and operate best with numbers and information about who we are talking to and why."

So with the brand deep-dive underway, it quickly became apparent that research would be needed to help fill the knowledge gaps. Enter Benenson Strategy Group (BSG), a top strategic research consultancy that advises many of the world's most successful corporations, heads of state, and institutions. Joel Benenson, Founding Partner and CEO, had come to know David and Susan Axelrod, hearing their personal stories of epilepsy as he and David worked together on two presidential campaigns.

So when approached with our research assignment, Joel generously offered the support of his firm. "People just don't talk about epilepsy. There is very low recognition of it, way below heart disease and cancers and even Alzheimer's and Parkinson's," he said.

"We have a lot of requests to do pro bono work, but Donny felt CURE was different. Different because epilepsy impacts so many families. Different because, unlike other diseases that seem to have almost universal understanding, epilepsy seems to be largely misunderstood and out of mind of the general public."

The research proved this. More than 500 people whose lives have been affected by epilepsy were surveyed, and although they expressed a clear awareness of the condition's serious effects and consequences, they had not donated to epilepsy-related causes at nearly the same rate as to others, such as cancer research. "And with the squeeze on all non-profits to raise dollars for research, having an awareness problem makes it even more challenging. We work with these types of challenges every day and applied the same techniques to CURE."



Danny Franklin, a partner at BSG, said, “Our approach to research is to discover how people see the world around them and what motivates them to engage in that world. For CURE it meant discovering how donors and other constituents connect to the CURE vision. It’s hard to get people motivated about medical research unless it is humanized in a way that people understand.”

Speaking for the entire BSG team, Danny said, “What makes this work especially rewarding is we’re not just selling another item out of the grocery store. We’re helping frame the discussion around a topic that can save lives, eliminate the suffering of patients and their families and one day find a cure for epilepsy. We’re proud of the results and our involvement with CURE.”

To sum up both teams’ work, Tyler said, “The research that BSG was able to provide allowed us to better inform, confirm and optimize our thinking around why people get involved, what’s important to them, and ultimately how best to formulate communications that would inspire people to invest in this cause – both through time and money.”

The incredible talent and generosity of these two groups has helped us uncover actionable intelligence and insights into donor profiles and strategies; we’re better equipped to drive the conversation and educate people on epilepsy, research and CURE’s impact. The involvement of the individuals from BSG and Deutsch is helping us shape and improve our efforts in defining, communicating and living the CURE brand.

In October 2014 at our New York City reception, we were honored to recognize BSG & Deutsch for their contributions, not only to CURE, but also to the entire epilepsy community.



Benenson Strategy Group (top photo) and Deutsch with Susan Axelrod at the NYC CURE event.





“I didn’t used to like to talk about it,  
but now I do. **You know why?**  
I realized that if I didn’t talk about it,  
nobody would care about epilepsy.”

Virginia Cooper

DAUGHTER OF KATE NEALE COOPER, CURE CREW





# Ragnar Relay/Kate Cooper

CURE Crew Fundraiser

“So, you know how in October you go to a store and there’s pink everywhere? Yogurt, sports bras, everything is painted pink for Breast Cancer Awareness Month. October makes me frustrated because no one does the same thing for epilepsy.”

Those words, written by Virginia Cooper, lead off the “Violet Femmes” donor page for her mother Kate’s Ragnar Relay team. They run the race to raise awareness for epilepsy and dollars for CURE. It might seem a simple observation for a 12-year old girl, but according to Kate, “She’s not an average 12-year-old.” Her daughter was diagnosed with epilepsy at just 17 months. Kate adds, “My husband, Matt, and I estimate she’s suffered more than 12,000 seizures despite the many medications she takes every day.” Like Virginia, nearly half of the three million Americans with epilepsy do not have complete seizure control or only achieve seizure control at the cost of debilitating side effects from medications.

About 1 percent of children under age 17 have been diagnosed with epilepsy or a seizure disorder, and says Virginia, “I am one of those children.” She goes on to write in the Violet Femmes’ introduction, “My seizures are different every time. Sometimes I have absence seizures, where I just stare into space, and sometimes I have tonic seizures, which are bigger and more serious. When I feel those coming, I get down on the ground because I know I won’t be able to control my body. There’s no way to describe how that feels. For a while when I was little, I had about 60 of those a day.”

But the life of a 12-year old girl, even one with epilepsy, is about so much more. It’s about learning, socializing, thinking about the future: Where to go to college? And what will life look like outside the familiar surroundings of home? So today, Virginia’s mother says, “Our job is to prepare her for life without us by her side, teaching her how to take on her disease.” And that means more than Virginia taking medications: it means being an active participant in her own medical care – including having a relationship with her doctor that feels right to her. It means accepting that she will never swim in the ocean without a life jacket or drive a car, although Virginia is still holding out hope that technological advancements will make driverless cars a reality sooner rather than later.

And, as Virginia begins to take on more of the management of her disease, her voice has gotten a little stronger in speaking about the disease from her point of view. She continues on the Violet Femmes page, “It sometimes felt like I was the only one in the world with epilepsy, but that’s not true. More than 3 million people in the United States alone have the disorder! But I did not realize that until I was 11 years old because people don’t like to talk about it. I didn’t used to like to talk about it either, but now I do. You know why? I realized that if I didn’t talk about it, nobody would care about epilepsy. We need to educate people about epilepsy so they don’t joke about it and so that they care about finding a cure.”





According to her mother, “I read these words written by my daughter and I’m struck how the patient is becoming the activist. I’ve been telling Virginia’s story almost her entire life. But, at some point over the past few years, it dawned on my husband and me that Virginia’s story is now her story to tell. She has the power to change people’s minds. And she is getting more comfortable with that role as time goes by.”

Raising awareness and funds to support research will always be important to Kate and Matt. “We have the time and the resources to be proactively involved in finding a cure,” she says. It’s why in 2014 she formed a Ragnar Relay team. “One of the ways I cope with the stress of raising a child with epilepsy is by running. I often run with friends, who often ask what they can do to help. So I asked them to join my team. We call ourselves the Violet Femmes. My clever friend Vicki came up with our team name because purple is the color of epilepsy awareness and we’re an all-female team.”

The 2014 Ragnar they ran is a 200-mile race from Cumberland, Maryland, to Washington DC. “In case you’re unclear about the format,” Kate says, “here’s how it works: we divided our team of 12 runners into two minivans. Each runner ran three pre-determined legs, varying in length from 2.2 to 11.1 miles. We ran day and night, with a couple of brief opportunities to roll out a sleeping bag for a quick nap. It was logistically challenging, mentally daunting and physically exhausting – and I’d do it all again tomorrow. I hadn’t realized how much I missed being on a team, and this was a dream team.”

Virginia closes the Violet Femmes page by writing: “I am so proud of my mom and all her friends—they are amazing women. Alison Kukla, one of my mom’s teammates, has epilepsy and is an inspiration to me. It’s cool to see an adult living with epilepsy – she proves how strong we all are.”

As part of the CURE Crew, The Violet Femmes raised more than \$30,000 in 2014. We want to thank every one of the runners, their families and all who supported them along the way.







## The Vogelsteins

### Multi-generational Giving

When Evelyn Nussenbaum first read about Susan Axelrod and CURE, she says, “I was desperate. If I couldn’t help my own kid I wanted to help get to the bottom of this nasty disease and stamp it out. Figuring out how epilepsy worked and how to kill it was Goal One for me.” When she met Susan, she adds, “I knew I was going to throw my lot in with this woman.”

One of our biggest supporters, Evelyn has served on our board for the past four years and is always first to raise her hand to do whatever is needed. But what makes someone so devoted to help? That’s the story of Sam Vogelstein, her son, and of their entire extended family, who turned a struggle into a mission and a mission into a potentially life-changing gift for current and future epilepsy patients around the world.

Evelyn recounts the story: “Sam, now 14, had his first seizure when he was four-and-a-half. It wasn’t a typical seizure. He bent quickly at the waist, as though he were bowing to start a judo match – so it took us a couple months to figure out what it was. When it began happening more frequently, we called the doctor. By then, it was happening once a week and he was starting to get hurt. Once he smashed his head into a window. Another time one of these ‘bows’ happened at the top of the stairs and he fell down the entire flight. And they were near impossible to control. At one point, he was having 100 seizures a day.

“They were a rare kind, called myoclonic absence. And it changed everything for us. As a family, we lost all sense of normality and safety. We never knew how bad the seizures were going to be and how bad the side effects from the

medicines would be. [My husband and Sam’s father] Fred and I never knew when we would get a phone call because he had hurt himself or because he was having so many seizures he couldn’t focus in school. Both of us were in danger of losing our jobs, and I ultimately gave up my career so at least one of us could have one. It turned our daughter, Bea, into more or less permanent second fiddle.”

But somehow the Vogelsteins turned this painfully familiar story of a young boy with epilepsy into something much greater. In their search for a cure to Sam’s seizures they looked everywhere, tried every conventional therapy – including an autoimmune therapy using intravenous immunoglobulin and a high-fat medical diet. The treatments that showed some results didn’t work for very long or had worrisome side effects. Finally, the family tried a new course of therapy that would not only prove successful in treating Sam’s seizures, it would open up a line of non-traditional therapy that could potentially help thousands.

This therapy involves a derivative of cannabis called cannabidiol or CBD. Removing the majority of tetrahydrocannabinol, or THC, in a distilled tincture to produce specific strand of CBD removes the properties that would make Sam high, leaving those properties that can calm his seizures. Fred Vogelstein writes about the entire process, from discussing cannabis as a solution to clearing all U.S. hurdles and getting imported CBD from England, in a 2015 Wired Magazine article: “One Man’s Desperate Quest To Cure His Son’s Epilepsy – With Weed.” (<http://www.wired.com/2015/07/medical-marijuana-epilepsy/>)

SAM, NOW  
14, HAD  
HIS FIRST  
SEIZURE  
WHEN HE WAS  
4 AND A HALF.  
IT WASN'T  
A TYPICAL  
SEIZURE.





And as you can imagine, it was not a short, simple or inexpensive journey. Fred writes in the article: “It appears our enormous bill for helping Sam has also jump-started the development of what doctors tell us could be one of the most exciting new drugs to treat epilepsy in a generation.”

But the story doesn't end there. While Sam is nearly seizure-free and, in the words of his parents, “living like a normal boy,” they are still proactively searching for a way to eliminate the last of his seizures. In the process of Sam's journey, Fred's father and his wife, John and Barbara Vogelstein, became actively involved in the process of helping clear the way for getting CBD imported from England.

And they didn't stop there. The John & Barbara Vogelstein Foundation has graciously given to CURE as the primary sponsor of our signature program, the Epilepsy Genetics Initiative (EGI). “We know how devastating epilepsy can be. We're confident that with CURE's leadership, EGI can provide families with answers, and researchers with the tools to find a cure,” John says.

Even Fred and Evelyn's daughter, Bea, has thrown her support toward finding a cure, asking people to give to CURE for her Bat Mitzvah instead of giving gifts to her. She explains: “I don't just feel obligated to do it. It's the right thing to do. It's important to me to do something to help.”

It's remarkable what one multi-generational family is doing to “get to the bottom of this nasty disease and stamp it out,” as Evelyn puts it. We are proud to count them as members of the CURE family. And it is heartening and gratifying to hear Sam tell his own story today.





## Sharon O'Keefe

Board of Directors Chair

Hope is not a word tossed around lightly by academics in medicine. Their lives are about finding therapies, about treatments and protocols, and clinical and scientific research. They thrive on rigor. But, when that academic is the mother of a child with epilepsy, hope can be the comfort your child needs.

As Sharon O'Keefe, newly seated Chair of CURE's Board of Directors and the President of the University of Chicago Medical Center says, "While my daughter, Mackenzie's seizures are reasonably under control she still has the occasional breakthrough seizure, and following these she will often ask if CURE is working to help her. There is nothing more motivating and rewarding than to look her in the eye and assure her that everyone at CURE and researchers around the world are working for not just her but for all the millions of people who live with epilepsy everyday. Science is the answer, but the Mackenzies of the world are the reason why."

Sharon brings a unique perspective to her role at CURE. "CURE resonates with me and my family, as our daughter was diagnosed at age 5 with a childhood seizure disorder, Doose Syndrome, which is not easily controlled by conventional medication therapy. It is 'idiopathic,' meaning the cause is not known. Like many of the epilepsy syndromes, research holds out the hope of generating new knowledge about the causes of epilepsy – and the prospect of new therapies and eventually a cure to eliminate the disease. Personally, Mackenzie is why I want to be involved with CURE."

Professionally, Sharon has dedicated her career to academic medicine. "The academic environment is committed to advancing knowledge and offering advanced therapies to those challenged by complex diseases. I enjoy working with the research community and have learned over time what is needed to fuel innovation and discovery."

And because CURE sits at the intersection of her personal passion and her professional commitment, she feels well positioned to contribute to CURE's core mission. "Rarely does one find an opportunity that provides such great personal and professional satisfaction," she says. "And it all happened quite organically."

**"Science is the answer,  
but the Mackenzies of the  
world are the reason why."**

When Sharon and her family moved back to Chicago in 2010 she began looking for a neurologist for Mackenzie. The doctor she met with mentioned CURE and suggested she look into the organization. "Knowing my high regard for research and my personal experience with Mackenzie's clinical journey, he felt it might be a place for me to get involved," she says.





It started with an unsolicited email to Susan Axelrod asking how she might get involved with CURE, and her first interaction was to spend time with the Scientific Advisory Board, as an observer. “One meeting and I was hooked!” she says. “What I saw was an amazing energy among superb scientific leaders to take on the great challenge of fostering breakthroughs in the field of epilepsy research.”

She then met with Susan over dinner and felt a close connection with her passion and Susan’s own story of her daughter, Lauren. She soon joined the board of CURE and has recently taken the role of Board Chair. “The purpose, the people and their passion just grab you, and I’m fully committed to advancing the cause. There is no better cause to which to devote my time and energy.”

When asked about the accomplishments of CURE and the road ahead, Sharon has this to say: “While I am still early in my term, I believe CURE has the ability to foster innovation as exemplified by the Epilepsy Genetics Initiative (EGI) and to focus on some of the most challenging areas such as infantile spasms and sudden unexpected death in epilepsy (SUDEP). CURE is also able to facilitate collaboration by funding team science; discovery increasingly requires many disciplines to work together. CURE can drive cross-disciplinary research. And finally, CURE can support young investigators and fill the pipeline with more and more researchers dedicated to finding a cure for epilepsy.”

As both a mother and an academic leader, Sharon will dedicate her time as Chair to raising awareness of the impact of this disease, and to raising resources to fuel innovative research into its underlying causes. In short, to move closer to a cure for epilepsy.



# 2014 Signature Events

At CURE we are fortunate to hear hundreds of stories of people getting involved to help us every year. We are amazed by them. We are humbled by them. This year we've chosen to highlight four stories that tell the CURE story through the hearts and minds of some of these incredible people and organizations.



## **CHICAGO BENEFIT**

Featuring James Taylor

May, 2014



## **NYC BENEFIT**

"Toasting New York State of Minds"

October, 2014



## **BOSTON BENEFIT**

Featuring Carole King

November, 2014



**CHICAGO BENEFIT**  
**Featuring James Taylor**  
May, 2014

Singer/songwriter James Taylor provided the musical accompaniment and continued the emotional tone of our 2014 CURE Chicago Benefit. It was an evening that brought together leaders in sports, business, philanthropy and politics to raise money for epilepsy awareness and research, with many sharing their very personal stories of how the disease has impacted their lives and the lives of their families. As always, these stories resonated throughout the room as a reminder to everyone why CURE's role in funding research is so important – to end suffering and to save lives.







#### NYC BENEFIT

### “Toasting New York State of Minds”

October, 2014

Our New York reception was a night of personal stories, recognition of profound efforts, and the announcement of the New York Friends of CURE grant, named for generous support of the New York community and in memory of Danny Tromberg. We took a few minutes from our standard program to thank the leaders of two New York City firms that gave their hearts, talent and expertise to helping CURE find new ways to communicate and engage people in our vision. We thanked Joel Benenson, Donny Deutsch and their tireless teams not only as dedicated professionals, but also as passionate believers that working together can make lives better.





**BOSTON BENEFIT**  
Featuring Carole King

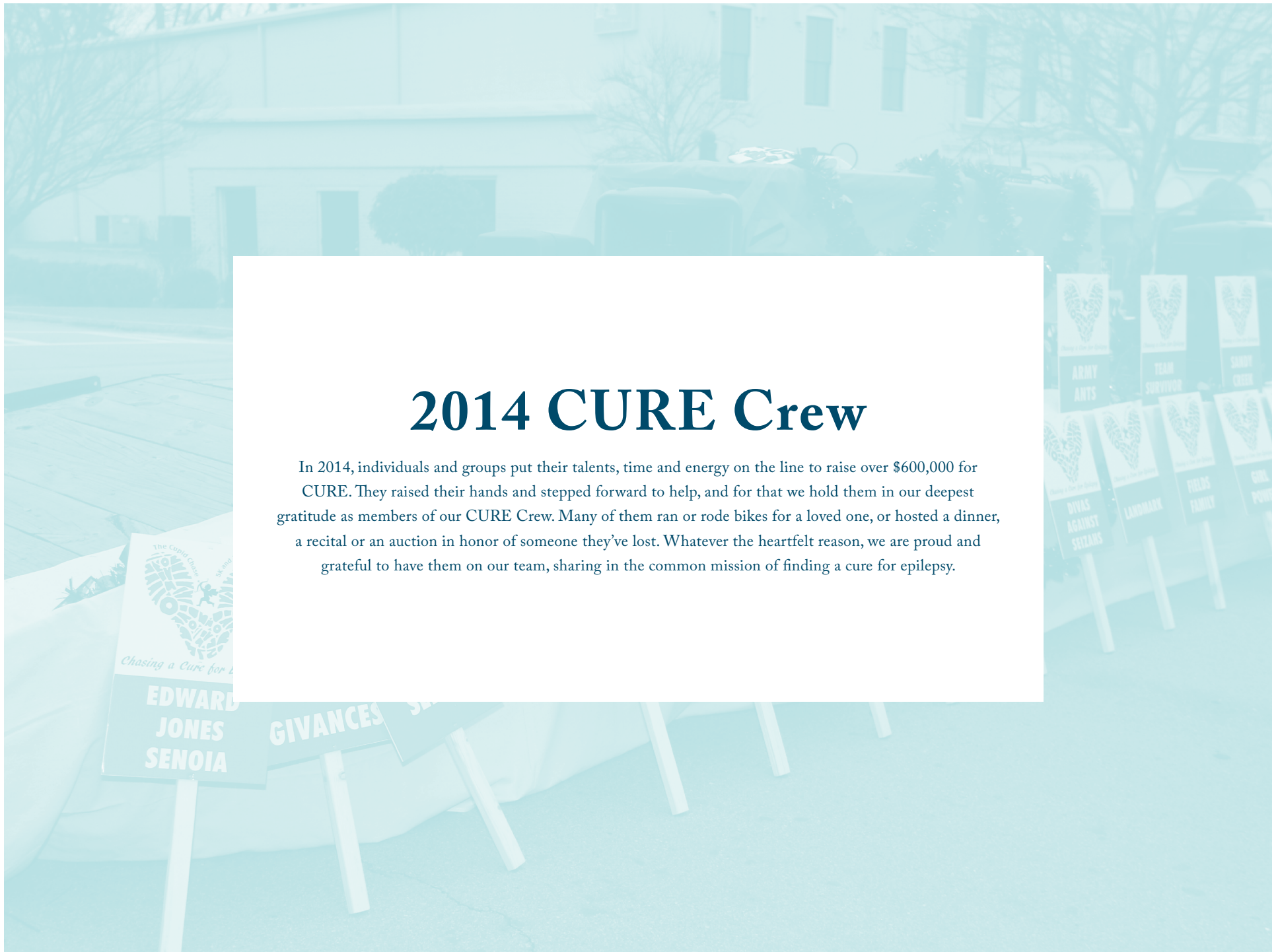
November, 2014

Enthusiastic, hopeful and courageous. These are some of the words we use when describing the people affected by epilepsy and those who work tirelessly each day to find a cure. That spirit was alive and well at our Boston Benefit. The theme “Every Moment is an Opportunity” proved to be spot-on: the event was an opportunity to bring together some of the city’s most talented, generous and supportive leaders and philanthropists. An opportunity to share stories. An opportunity to educate and learn. And an opportunity to be entertained by an American cultural icon, Carole King.



# 2014 CURE Crew

In 2014, individuals and groups put their talents, time and energy on the line to raise over \$600,000 for CURE. They raised their hands and stepped forward to help, and for that we hold them in our deepest gratitude as members of our CURE Crew. Many of them ran or rode bikes for a loved one, or hosted a dinner, a recital or an auction in honor of someone they've lost. Whatever the heartfelt reason, we are proud and grateful to have them on our team, sharing in the common mission of finding a cure for epilepsy.



## \$100,000 & Above



### Drive for CURE WHEATON, IL

Hosted by Susan and Jim Schneider, Drive for CURE celebrated its 10th annual golf outing in 2014. The event raised more than \$125,000, funding the Julie's Hope named grant in honor of their daughter who has fought epilepsy most of her life.



### HOPE4SUDEP WORLDWIDE

HOPE 4 SUDEP was founded by Ellen Benninghoven in memory of her son Cameron, who passed away from Sudden Unexpected Death in Epilepsy (SUDEP) in 2009. The campaign raises awareness and funds for epilepsy research – specifically SUDEP – and has helped fund numerous grants named in Cameron's honor.



### S4 Epilepsy Walk SOUTHBURY, CT

Since its inception in 2012, the S4 Epilepsy Walk, Dinner and Silent Auction has raised more than \$320,000, naming three grants for epilepsy research. Founded for Sarah Fradkin, the all-day event brings more than 600 family, friends and members of the community together for a day of fun activities dedicated to raising awareness and funds for epilepsy research.

**\$25,000–\$99,999**

The British Invasion	Madison, WI
Building CURE Globally	Worldwide
Ragnar Relay Race: The Violet Femmes	Washington, DC

**\$10,000–\$24,999**

4th Annual Teresa's Birthday Benefit for CURE	San Francisco, CA
Bag a CURE	Andover, MA
Calvin's Story	Brunswick, ME
The Cupid Chase	Senoia, GA
CURE365	Northbrook, IL
Hugh-A-Thon	Western Springs, IL
Joey's Song	Madison, WI
Madison Friends of CURE	Madison, WI
RE: Epilepsy	Highwood, IL

**\$2,500–\$9,999**

11th Annual Kyle's Run for a Memory 5K	Victor, NY
Ben Morgan Recital	Fairbanks, AK
Clipper Round the World	Worldwide
CURE Purple	Manchester, NH
Shutouts for Seizures	McHenry, IL

**\$1,000–\$2,499**

5K Strides for Epilepsy	Salisbury, MD
Anna's Memorial Day 5K and Fun Walk	Middletown, MD
Christine's Marathon Fundraising	Philadelphia, PA
Epilepsy Awareness Yard Sale	Sudbury, ON
Rebounds for CURE	Cleveland, OH
Seize the CURE for Seizures	Los Angeles, CA
Sip for a CURE	Arlington, VA
Team Ethan and Liam	Erie, PA
Team Scott 5K	Hoboken, NJ
Volley for the CURE	Urbana, IL

**UP TO \$1,000**

3rd Annual Silent Auction for CURE	Ames, IA
Big Sur Marathon	Big Sur, CA
Cornhole for CURE	Ludington, MI
Faces of America Bike Ride	Washington, DC
Ian Hallum Concert	Sherwood, AR
Jake Knuese Golf Outing	New Berlin, WI
Pose for a CURE	Whitman, MA
Pumpkin Art Project	Highwood, IL
Team B.E.N.	Atlanta, GA
TJ Stewart Memorial Benefit	Rocky River, OH





# Finances



# STATEMENT OF FINANCIAL POSITION

Years ended December 31, 2014, 2013

		2014			2013		
		Unrestricted	Temporarily Restricted	Total	Unrestricted	Temporarily Restricted	Total
<b>ASSETS</b>	Cash and cash equivalents	\$2,003,819	\$350,000	\$2,353,819	\$2,930,436	–	\$2,930,436
	Investments	7,011,355	–	7,011,355	6,853,344	–	6,853,344
	Contributions and grants receivable	78,086	420,000	498,086	279,039	250,000	529,039
	Prepaid expenses and other assets	59,266	–	59,266	78,673	–	78,673
	Fixed assets, at cost less accumulated depreciation of \$13,858 in 2014 and \$18,327 in 2013	45,338		45,338	25,616		25,616
	<b>Total Assets</b>	<b>9,197,864</b>	<b>770,000</b>	<b>9,967,864</b>	<b>10,167,108</b>	<b>250,000</b>	<b>10,417,108</b>
<b>LIABILITIES</b>	Accounts payable and accrued expenses	132,851	–	132,851	74,605	–	74,605
	Grants payable	2,819,948	–	2,819,948	1,953,495	–	1,953,495
	<b>Total Liabilities</b>	<b>2,952,799</b>	<b>–</b>	<b>2,952,799</b>	<b>2,028,100</b>	<b>–</b>	<b>2,028,100</b>
<b>NET ASSETS</b>	<b>Net Assets</b>	<b>6,245,065</b>	<b>770,000</b>	<b>7,015,065</b>	<b>8,139,008</b>	<b>250,000</b>	<b>8,389,008</b>
	<b>Total Liabilities and Net Assets</b>	<b>\$9,197,864</b>	<b>\$770,000</b>	<b>\$9,967,864</b>	<b>\$10,167,108</b>	<b>\$250,000</b>	<b>\$10,417,108</b>

# STATEMENTS OF ACTIVITIES AND CHANGES IN NET ASSETS

Years ended December 31, 2014, 2013

			2014			2013		
			Unrestricted	Temporarily Restricted	Total	Unrestricted	Temporarily Restricted	Total
<b>SUPPORT AND REVENUE</b>								
<b>Contributions</b>	Foundations		\$80,483	\$650,000	\$730,483	\$869,970	\$250,000	\$1,119,970
	Corporate		47,240	–	47,240	133,306	–	133,306
	Individuals		620,767	120,000	740,767	503,889	–	503,889
	Other		1,988	–	1,988	–	–	–
	In-kind		123,370	–	123,370	40,000	–	40,000
<b>Special Event</b>	Proceeds		4,235,501	–	4,235,501	2,928,510	–	2,928,510
	Expenses		(662,333)	–	(662,333)	(427,374)	–	(427,374)
	Net Special Events		3,573,168	–	3,573,168	2,501,136	–	2,501,136
	Interest and Dividends		181,509	–	181,509	186,840	–	186,840
	Other		8,108	–	8,108	5,293	–	5,293
	Net Assets Released from Restriction		250,000	(250,000)	–	516,666	(516,666)	–
	<b>Total Support and Revenue</b>		<b>4,886,633</b>	<b>520,000</b>	<b>5,406,633</b>	<b>4,757,100</b>	<b>(266,666)</b>	<b>4,490,434</b>
<b>EXPENSES</b>								
	Program Services		6,173,066	–	6,173,066	3,857,121	–	3,857,121
	General Administration		366,218	–	366,218	224,593	–	224,593
	Fundraising		181,164	–	181,164	308,309	–	308,309
	<b>Total Expenses</b>		<b>6,720,448</b>	<b>–</b>	<b>6,720,448</b>	<b>4,390,023</b>	<b>–</b>	<b>4,390,023</b>
	Change in Net Assets Before Change in Fair Value of Investments		(1,833,815)	520,000	(1,313,815)	367,077	(266,666)	100,411
	Change in Fair Value of Investments		(60,128)	–	(60,128)	98,515	–	98,515
	Total Change in Net Assets		(1,893,943)	520,000	(1,373,943)	465,592	(266,666)	198,926
	Net Assets, Beginning of Year		8,139,008	250,000	8,389,008	7,673,416	516,666	8,190,082
	<b>Net Assets, End of Year</b>		<b>\$6,245,065</b>	<b>\$770,000</b>	<b>\$7,015,065</b>	<b>\$8,139,008</b>	<b>\$250,000</b>	<b>\$8,389,008</b>

# 2014 Donor List

# 2014 Donor List

## \$250,000 AND ABOVE

Bloomberg Philanthropies  
Constance Milstein and Family

## \$100,000–\$249,999

Alexandria Real Estate Equities, Inc.  
Bank of America  
Cafaro-Livingston Charitable Trust  
Eisai, Inc.  
Sunovion Pharmaceuticals, Inc.

## \$50,000–\$99,999

BAND Foundation  
Fred Eychaner  
GCM Grosvenor  
Hill Holliday  
Katten Muchin Rosenman LLP  
Michele and Howard Kessler  
Deborah Kirshner and Paul Heldman  
Gardiner and Nicholas Lapham  
Emily Sachs Wong and Thad Wong  
Starcom  
Isaiah Stone Foundation  
Suffolk Construction's Red and Blue Foundation  
Ventas, Inc.  
Wachtell, Lipton, Rosen & Katz  
Young & Rubicam

## \$25,000–\$49,999

Aon  
Susan and David Axelrod  
Joel and Lisa Benenson Foundation  
Centerview Partners LLC  
Eileen and Jack Connors  
The Crown Family  
Development Specialists, Inc.  
Endurance International Group  
Equity Residential Properties Trust  
Anne Finucane and Mike Barnicle  
Jane P. Gannaway  
Carol A. Jones and Thomas F. Hynes  
Bernadette Keller and William M. Daley  
Jesse and Joan Kupferberg Family Foundation  
Lisa and Raymond Lewis  
Lippincott  
Mesirow Financial  
New England Patriots Charitable Foundation  
Mark Ordan  
Partners HealthCare  
Sacks Family Foundation  
Lois and Leonard Sharzer  
UCB, Inc.  
University of Chicago Medicine  
John and Barbara Vogelstein Foundation  
Alexandra Wentworth and George Stephanopoulos



# 2014 Donor List (cont.)

## \$10,000–\$24,999

---

AKPD Message and Media LLC	Allison and Brian Feltzin	Quonochontaug Foundation
Heidi and Craig Albert	Goldman Sachs	RBC Capital Markets
All the Way Foundation	Larry Grisolano	Molly Reinhart
Allied Telesis Inc.	John W. Henry Family Foundation	Rich May
AMLI Residential Properties Trust	The Hubbell Group	Jennifer and Jeffrey Robinson
ASGK Public Strategies, LLC	Celia and Daniel Huber	Paula Robinson
Atria Senior Living	John Hancock	Michele Schara and Randy Mehrberg
Autism Speaks	Kaim Family Foundation	Susan and Jim Schneider
Sarah and Paul Auvil	Andrea and Stephen Kaneb	Elaine and Gerald Schuster
AWH Foundation	Kekst and Company	Tom Shields and Family
Barack Ferrazzano Kirschbaum & Nagelberg LLP	Kindred Healthcare	Stefani's Children's Foundation
Ellen Benninghoven and Michael Schafer	Kirkland & Ellis LLP	The Strategy Group
Blue Engine Message and Media, Inc.	Richard L. Landau	TPN
BMO Harris Bank	Lift A Life Foundation	UBS Securities, LLC
Boathouse Inc.	Lundbeck LLC	The University of Chicago
Brixmor Property Group	The Steve Mason Family	Walgreens Co.
Bully Pulpit Interactive	John R. Miller	Patty and Dan Walsh
Coeur Mining	Mintz, Levin, Cohn, Ferris, Glovsky and Popeo, P.C.	Weber Shandwick
Comcast Corporation	Jacqueline and Frank Napolitano	Wells Fargo Bank
Dara and John Corkery	Northeast Utilities	Kathryn and Steve White
Shalee and Blake Cunneen	Northern Trust	Yum! Brands Foundation
John Del Cecato	Octagon	
Donald Deutsch	Katherine and Joseph O'Donnell	
Karen K. Dixon and Nan Schaffer	Sharon O'Keefe and Hal Moore	
Duncan Family Foundation	Pircher, Nichols & Meeks	
Beth, Phil, Kristine, Leigh Anne, and April Emery	PNC Bank	
Ernst and Young LLP	Linda and Richard Price and Family	
Exelon	Pritzker Traubert Family Foundation	
	Putnam Investments	

# 2014 Donor List (cont.)

## \$5,000–\$9,999

312 Spirits	Jennifer and Peter Flaherty	Jill and Paul Meister	Patricia and Glen Tullman
AAR Corporation	Erin and Justin Foley	Melcher + Tucker Consultants	UFCW Charity Golf Classic, Inc.
Roger Ailes	Fredricksen Green Foundation Fund at the Community Foundation of Western Nevada	Sara and Patrick Nash	Upsher-Smith Laboratories, Inc.
Hope and Joe Albert	Suzanne and Albert Friedman	The Oak Foundation	William Blair and Company
Analytics Media Group	Jody and Mark Furlong	Amy and Jim O'Donnell	Connie Wishner
Anonymous	Lally Graham Weymouth	Audrey and Claude Ohanesian	Deb and Seth Wohlberg
Ariel Investments	Greenberg Traurig LLP	Osprey Foundation	Tina and Joe Wolf
Liz and Mike Axelrod	Audrey Holder	Lee and Herman Ostrow Family Foundation	Danielle and Bob Wolters
B.Braun CeGat, LLC	Eleanor and David John Holloway	Patrick Padden, Jr.	Andrea and Francis Ziegler
Bain and Company, Inc.	Russell Horwitz	Michele and Mark Patterson	
Barclays	Houlihan Lokey	Perkins Coie LLC	
Ann and Doug Benschoter	Nancy and Tim Iida	PLM Foundation	
Blue Cross Blue Shield of Illinois	Jenner and Block LLP	Polly and Kenneth Rattner	
The Boston Foundation	Kathy and Arthur Judd	Loretta and Michael Robinson	
Brand Union	Susan and Jules Kaufman	The Roche Family Foundation	
Willard Bransky	Barbara Kelly	Irene Rosenfeld and Richard Illgen	
Justice Anne Burke and Honorable Edward M. Burke	Kroger	Mary and Glenn Rufrano	
C2S Enterprises, Inc.	Lateef Investment Management	Bettylu and Paul Saltzman	
Cabrera Capital Markets, LLC	Andrea Lavin Solow and Alan Solow	Luella and Alan Schneider	
Marcy and Gregory Carlin	Judy and Scott Leisher	Wendy and Richard Schneider	
Catamaran	Leonard R. Friedman Risk Management	Janet and Alan Sear	
Chicago Bears Football Club, Inc.	Toby and Greg Lewis	Kerry Shannon and Steve Byrne	
Christie's	Mary and Lawrence Liebscher	Valerie and Lee Shapiro Family	
Deborah and Donald Cisle	Lunsford Capital	Sidley Austin LLP	
Cyberonics	Ann & Robert H. Lurie Children's Hospital of Chicago	Adam Smyth	
Dan Klores Communications	Daina Lyons and Forrest Claypool	SS+K	
Daryl Deel	The Malkin Family	Diana and Doug Stewart	
DeVry University	Mallinckrodt Pharmaceuticals	Leslie and David Storch	
Dewey Square Group, LLC	Linda McFadden	Eileen and Thomas Sutula	
Duburg Iron Works, Inc.	Meckler Bulger Tilson Marick and Pearson	Telemundo	
		Beth and Nathan Tross	

# 2014 Donor List (cont.)

## \$2,500–\$4,999

---

Adams Foam Rubber Company	Sheri and Mark Jessell	Jody and Ross Silverman
Diane Aixala and Gavin Campbell	Melinda and Walter Kelly	Bradford Sippy
Alario Group	Deborah Kiley	Judith and Mark Standefer
Anne and John Amboian	George Koether	Donna and Joel Stender
Anonymous	Eugene and Janet Lerner Family Foundation	Gloria Stender
Barbara and James Beard	Faye and Daniel Levin	Sterling Risk
Bears Care	Desiree Lynch	Robin Stern
Blum-Kovler Foundation	Don MacDonald	John M. and Joan F. Thalheimer Family Charitable Foundation
Kimberly Borden	Hadrian and Randy Markowitz	The Family of John and Bette Troy
Ellen and Orran Brown	Hanne and John Messerich	Univision Local Media
Margaret Brown	John and Elena Minardi	The Waldman Family Charitable Trust
Nicole and Matthew Carlin	Steve Moore	Laura and Bruce White
Candy Chan	David Morrisey	Wilson Elser Moskowitz Edelman & Dicker LLP
DLA Piper LLP	Much Shelist	Bertie and Anthony Woeltz
Douglass Winthrop Advisors	Suzanne and Terrence Murray	
The Duda Family Foundation	Northwest Pulmonary Associates, S.C.	
Yasminda and Brian Duwe	Sanford Perl	
F.H. Paschen, S.N. Nielsen	David Petcove	
Fiduciary Trust Company International	Precision Strategies	
Sally and John Filan	Rail Exchange, Inc.	
Carol and Bernie Fulp	Julie and Robert Ramirez	
Debbie Gannaway	Ken Raskin	
Brad Gerow	Regan Communications Group, Inc.	
Andrew Giangrave	Joanne Reynolds	
Jon and Mindy Gray Family Foundation	The Patrick Ring Foundation Inc.	
Grodsky Caporrino & Kaufman LLP	Rory Group, LLC	
Ambassador Fay Hartog-Levin	Margot and David Rosenbaum	
John Heilemann	Maureen and Marc Schulman	
Kristin and Scott Hodges	Matt Schumacher	
Judith and Thomas C. Hynes	Virginia Seggerman and Wayne Szypulski	
Richard Jasculca	Nada and Andrew Sherman	

# 2014 Donor List (cont.)

## \$1,000–\$2,499

1111 Foundation	Laura and David Brewer	Linda and Matthew Decker	Friends of Cancer Research
Scott Aberle	Brigham and Women's Hospital, Department of Neurology	Rick Del Giudice	Michael Fritchie
Diane Aigotti and John Satalic	Carolyn Brooks	Deprisco Jewelers	The Furst Foundation, Inc.
Marc Alberts	Amy Brooks-Kayal and Rana Kayal	Diana's Bananas, Inc.	Mary Gager
Rae Anne and Daniel Alvarez	Mika Brzezinski	Julia and Richard Diasio	Jill and Robert Gallery
Lisa and Joel Alvord	Abigail Burke	Kathryn and Andrew Dickman	Shiva Gangal
John Ambrogio	Angela Byrd and Eric Weil	Nathan Dinger	Tina and Bill Gannaway
The American Ireland Fund	Ryan Cairns	Dorothy and Bud Dobbins	Steven Garcia
American Junior Golf Foundation	Nancy Calcagnini	Alison Donalty and Chris Hampson	Marilynn Gardner
Loretta and Walter Anderson	Terri and Dave Callahan	Jeanne and Barry Donalty	Lois and Dennis Gates
Ellen and Jeff Angley	Capital One	Kelly Dougherty	Barbara and Charles Gattuso
Rebecca Anhang and Matthew Price	Lisa Carnoy	Noel Dunn	Roger Gay
Anonymous	Judith and Patrick Casey	Cynthia and Jack Durley	Sejal and Neil Gehani
Avamere	CEMEX Materials LLC	Joanne and Steven Edelson	Geneva Investment Management of Chicago
Bartol Charitable Foundation Inc.	Karen and Ronald Christensen	Joanna Edgell	Nancy and Michael Glass
Brenda Battle	Sarah and John Cobb	Edward M. Kennedy Institute	Anna Glazer
Michael Bearwald	Suzanne and Patrick Coffey	Carol Ellman and Brett Vassallo	Ben Godley
Cheryl Beil	Cogan and Power P.C.	Englund Trust UTA	Elena and Arthur Goldfedder
David Bellamy	Luis Collado	Epic Systems Corporation	Arla and Joel Gomberg
Louis Belletini	Congregation Beth Shalom	Excellus Health Plan, Inc.	Eric Gortner
Susan Berghoff	Kate and Matt Cooper	Albert Fay	John Grayson
Joan Bever and Bruce Leech	Darryl Copeland, Jr.	Feinberg and Associates	Stacy Graziano
David Binder	Leon Corkery	Randy and Steve Fifield	Greater Boston Chamber of Commerce
Blaine Blanchard	Mary Louise Crane-Ryan	Lynn Fleisher and John Roberts	Richard Green
James Bohnen	CS Capital Advisors, LLC	Jane and Jeffrey Folan	Kathryn Griffin and James Drury
Jeffrey Boutilier	Patti Jo and James Cunneen	Carolyn and Dan Fortin	Erin Grodnick
William Bowes, Jr.	Cushman & Wakefield	David Fox	Scott Gunnison
Barbara Brackenridge	Jennifer and Warren Dakin	Joele Frank	Lisa Gustavson
Shannon Brady	Jean D'Amico and David Mark	Jacqueline French	Stephen Hackney
Mimi and James Brault	Valerie Davis and Gene Wright	Mary Frey	Karen Hajjar
Debbi Brendel and Barron Wall		Kelly and Andrew Friendly	Harbin Family



# 2014 Donor List (cont.)

## \$1,000–\$2,499 (CONT.)

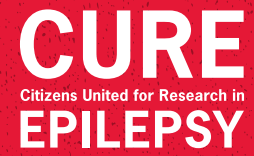
Robin and Michael Harding	Mark Karides	Karen and Barry Long	Michael Organ
Melanie and Andrew Harmon	Donna and Steven Katz	Roberta and Rick Lowell	John S. Osterweis
Irving Harris Foundation	Elizabeth and Alvin Katz	Stacey and Larry Lucchino	Ostrow Reisin Berk & Abrams Ltd.
Pam Hartford	KC Kitchen Coats and Family	W. Bruce Lunsford	Pilar Pablo
Kim and Alan Hartman	Mistie and Jason Keeler	Catherine Lyons	Christopher Pape
Karen Harty and Herb Goldberg	Christina and Kent Kelley	Madison Dearborn Partners, LLC	Manisha Patel
Sherry and John Healey	Susan and Robert Kelly	Laura and Alan Mantell	Deborah Peacock and Nate Korn
Anne Heldman	Vicki Kennedy	Kevin Martson	Carleton Pearl
Deirdre Henderson	Mark and Ann Killen Charitable Fund	Andrea Mathews	Daniel Perlman
Anne and Robert Hendrix	Leslie King-Grenier and Bart Grenier	Paula and Gregory Medlin	Terrie Pickerill and Bill Fuhry
Elizabeth and Jonathan Hirschtitt	Linda and Howard Kirschbaum	MedProperties Group	Milton Pinsky
Adam Hitchcock	Michelle and Andreas Klotz	Microsoft	Brenda Pluger
Patti Hobbs	Katie Koenig	Lindsay and Bradley Migdal	Lydia and Kenneth Polonsky
Albert Hofeld	Tim Kopko	Kathleen and John Morrissey	Christine and Linda Poulson
Kay Hoogland	Ron Krantz	Motorola Solutions Foundation	Rapp
Dr. Gayle A. Hoover and Rabbi Lawrence A. Hoffman	Jennifer Kroman and David Wermuth	Melissa Murdoch	Rattner Family Foundation
Michelle and Greg Horner	The Kenneth and Harriet Kupferberg Family Foundation	Michelle and Dennis Murray	Mary Helen and John Ray
Lynne Horning	Holly Diane Lane and Stuart Sorkin	Katherine and James Mutchnik	Peter Read, Jr.
Tammy and Gary Hundley	David Lapham and Stuart Mitchell	Gregory Mutz	Rightpoint Consulting, LLC
Illinois Tool Works Foundation	Burks B. Lapham	Elizabeth and Gary Nabel	Rimerman Family Foundation
Isabella Stewart Gardner Museum	Lawson Products, Inc.	The New England Council	Susan and Rick Riney
John Isley	Lawton Family	Alec Newman	Elizabeth and Gordon Robinson
Chad Jackson	Natalia Leons and Lawrence Yanowitch	George Nicholson	Janet and Howard Rose
Katherine Jackson	Cher and Roger Levin	Linda Nolten	Amy and Joshua Rosenow
James McHugh Construction Company	Lisa and Jonathan Levy	Northwest Infectious Disease Consultants	Laura and David Ross
Jocarno Fund	Michelle Ley	First Lady Michelle and President Barack Obama	Lori Rotskoff and Michael Canter
Kahn Brothers LLC	Liberty High School	Eleanor and Allan Odden	Ann and Paul Rutecki
Michael Kamienski	Janis and Corey Lindley	Celeste and Patrick O'Donnell	Christine and Bob Ryan
Kaplan Rosenow Family Foundation	LinkedIn	Lee O'Donnell	Matthew Ryan
Linda Kaplan	Jacqueline Logan and Whitney Magruder	Susan and Charles Offutt	SAS Architects & Planners
			John Sasso

# 2014 Donor List (cont.)

## \$1,000–\$2,499 (CONT.)

---

Savage Family Foundation	Rose and Dave Tyler
Janet and Glenn Schneider	Urbut Family
Cindy and Hal Schwartz	Christine and Scot Van Asten
Gloria and Jeff Schwartz	Jana Veliskova and Libor Velisek
The John and Evelyn Schweig Family Foundation	Murray and Kathleen Wachtel
Sear Family	Karen Walsh and James Berbee
Carol Showel	Diana and Stephen Ware
Lisa Siegartel	Waveland Investments, LLC
The Siegel Family	Barbara Weade and Michael Goc
Julie and Brian Sikkema	Roberta Weiner
Jeffrey Silver	Alice Weiss
Richard Simpson	Shirley and Arthur Weiss
Kerrin and Matt Slattery	Antoinette and Whitman Wheeler
Mark Slevin	Cheryl and Eric Whitaker
Michael Slotky	Wiley Rein LLP
Dianne and William Smart	Mark Wilkening
Katharine and Edwin Smith	Winn Family Charitable Foundation Inc.
Thomas Snyder	Stephen Winston
Marilyn and Julius Sparacino	Kelsey Wirth
Sara and James Star	Jori and Michael Witt
Andrea Stewart	Daniel Wolf
Svetlana and Howard Stillman	Steven Wolf, MD
Joanne Stroud	John Woodford
Marcia Stryker	Amy Yee and K. Eric Paulson
Honorable Elin Suleymanov	George Zelcs
Nancy and Stephen Summers	
Ambassador Louis and Marjorie Susman	
Kellie and Ernie Talarico	
Cynthia and Neal Toback	
Laura Tucker and Peter Giangreco	



# Thank You!



2014 ANNUAL REPORT