MESSAGE FROM CEO

Year after year, the Tourette Association of America reaffirms its position as the single best resource for the Tourette Syndrome and Tic Disorder community. From an idea hatched by four families around a kitchen table in 1972, the TAA has grown into a worldwide resource for people who would otherwise be wondering what to do in the face of a condition no one seems to understand. The TAA has been tirelessly raising awareness, investing in research, educating communities and professionals, and so much more.

We are especially proud of several accomplishments, our second virtual National Conference with over 2,000 attendees; the growth of our newest chapter model to ensure consistent and accessible boots on the ground support; and the development of our Neurodiverse Workforce Development Program, which prepares people with TS and co-occurring conditions with career training and vital information about the rights they have in the workplace.

As the effects of the COVID-19 pandemic persisted around the world and within our community, the TAA continued to innovate and develop resources specific to the new challenges the pandemic presented. With many people reporting increased isolation, struggles with mental health, and severity of tics, we adapted our services to the changing landscape and continued to grow as an organization. We saw a sharp increase in reported cases of sudden and rapid onset of tics worldwide. This phenomenon saw widespread interest from media outlets across the globe. The TAA created and disseminated resources about the common misconceptions and differences between Tourette Syndrome and Functional Neurological Disorder (FND) to the public.

The TAA continues to break new ground in the fight for people with Tourette Syndrome and Tic Disorders. Because of the dedication of our staff, volunteers, and donors, we can achieve our goal of meeting everyone affected exactly where they are and exactly when they need us.

Amanda Talty, President and CEO
MESSAGE FROM BOARD CHAIRMAN

I consider it a great honor to have been chosen to serve as the board chair for the Tourette Association of America. We have such a fantastic record of volunteerism and selflessness in our community, and this spirit of giving continually inspires me and my fellow board members in our commitment to ensure the TAA can help provide the best possible quality of life for people with TS and Tic Disorders. I would like to thank all the people who have given their time to the TAA.

Especially because Tourette Syndrome continues to be an underrepresented and underfunded disorder, we rely on our volunteers to ensure that we can accomplish our mission. Through the hardships of misunderstanding, stigma, and apathy that we all face as advocates, you have proven time and again that this community is unstoppable in the face of any adversity. Even as we continued to face the unique obstacles of COVID-19, our community did not back down because we know our vital work must continue moving forward. From our Youth Ambassadors and Rising Leaders to our Chapter Leaders, to event volunteers, all the way to my fellow board members, the TAA owes a debt of gratitude to everyone who has given their time and energy to our cause.

Stephen Barron, Board Chairman
161 Free Webinars/Facebook Lives
- Including a free Virtual Conference, with a concentrated 20+ educational programs, and targeted series designed specifically for COVID-19, adults, providers, young professionals, families, and children.

56 Educational and Medical Professional Programs
- Designed to educate health care providers, school administration and faculty, families, individuals and members of the general public, through in-person and online trainings.

45,195 Individuals Educated
- Through in-person and online trainings to health care providers, school personnel, families, individuals, and members of the general public.

3,123 Participants in Virtual #Rally4Tourette
- Represented TS on Virtual National Advocacy Day in Washington, D.C. through virtual meetings and take action letters. These advocates raised awareness for the most pressing issues facing the community.

3000+ Virtual Conference Registrants
- 60+ engagement opportunities, including webinars, interactive zoom sessions, live ‘hangout’ spaces, and a virtual concert
- 89% of attendees indicated that material presented at conference was “Useful” or “Very Useful”.
- 90% indicated that planned to use information learned in conference sessions to help with an individual or family need, or in their professional life.

MISSION DELIVERY HIGHLIGHT

Program Growth:
- 161 Free Webinars/Facebook Lives, more than double the amount of the previous year.
- 3,123 Participants in Virtual #Rally4Tourette almost double the amount of the previous year.

Digital Growth:
- With the challenges brought on by the Covid-19 pandemic, Tourette.org proved to be a tremendous resource for our heavily impacted community with over 830,000 users logging on for more than 1,000,000 sessions, resulting in over 1,600,000 pageviews
- Pages per session increased 7% year over year.
- “Find A Provider” traffic up 50% year over year.
- Access to Tourette Resources page up 66% year over year.
- Tools for Parents page up 107% year over year.
- Website language optimization ensured that general TS and Tic disorders online searches directly lead to 73% of the overall website traffic.
- Direct traffic (typing in the URL) was 13% of overall traffic.

5 Projects Funded to facilitate Cutting-Edge Research
- Aimed at paving the way for a deeper understanding of the condition, treatment and care options.

334 Volunteers
- The TAA invested in volunteer training programs to ensure uniform care and support is provided across the nation. These volunteers, including Youth Ambassadors and Rising Leaders, were equipped with tools to support local communities in raising awareness and general knowledge of TS.

Pilot Neurodiverse Workforce Development Initiative
- 75% of participants thought the mock interviews were helpful in preparing them for future interviews
- 83% found the feedback provided by the interviewer to be extremely helpful
Mental Health and Family Support

Supporting the mental health and wellbeing of the Tourette Syndrome (TS) and Tic Disorders community is at the heart of the TAA’s mission. Because more than 80 percent of people with TS or a Tic Disorders also have co-occurring mental health conditions, like ADHD, depression, anxiety, or OCD, it is critical that we invest not only in treatment for tics but also in the mental healthcare of our community. As the foremost champion for the TS community, the TAA offers an array of exclusive programs and resources that focus on getting individuals and families experiencing TS or Tic Disorders the mental health support that they need.

Our Information and Referral program (I&R) is the first line of contact for TS community members seeking resources and support. This year, the program introduced an automatic ChatBox feature on Tourette.org that allows visitors to receive automated personalized assistance to find the information they need. From there, visitors can request one-on-one referrals from the Information and Referral Manager. Through the ChatBox functionality, the TAA has doubled the number of referrals we’ve been able to provide.

The I&R team also invite community members to attend webinars and online support groups. This year, the TAA reached hundreds of participants nationwide who might otherwise be unable to access such support in-person. The focus of these resources ranges from managing stress, depression, anxiety, and substance abuse to suicide prevention and support. For the

“I found support groups in my area through the Tourette Association of America. I made life-long friends who encouraged me to still pursue my dreams. I learned to not let my diagnosis stop me from my dreams, and instead use it to encourage others like me.” —Madi
first time, we expanded our webinar series to include Spanish-speaking members of the community.

The TAA’s volunteers are the backbone of our mission, making 31 state chapters and 83 local support groups possible. This year, our volunteers expanded our support group network to include Georgia, Louisiana, and Washington/Oregon. Our community members often share that their local resources are some of the best ways for them to get involved and meet their peers.

As part of our goal to expand our reach into local communities nationwide, we launched our Chapter 2.0 initiative hiring Aisha Khan as fulltime Executive Director of our Southern California Chapter. This marks the first step towards growing state chapters to be a robust network of staffed branches that will give us an unprecedented capacity for local outreach and support.

**Training & Technical Assistance**

Because of a lack of awareness and research, the CDC estimates that more than 50 percent of people with Tourette Syndrome or Tic Disorders go completely undiagnosed. This leads many Americans to consider Tourette Syndrome to be a mild inconvenience that affects only a few people and unworthy of a second thought. The TAA’s Training & Technical Assistance program is the leading program in closing the knowledge gaps that prevent TS from being recognized for what it is: a widespread and serious disorder that affects the daily lives of millions of Americans.

The classroom is often the first place TS can present difficulties. This is why it is extremely important for educators to be aware of TS and receive training on how to help their students manage their tics. This year, we doubled the number of educational presentations in

“I went to many doctors... who couldn't make a diagnosis... In the end, it was a nice neurologist from a hospital that I had never heard of. Nowadays I do CBIT. I have gone through some hardships but made it through.”

—Callum
schools and hosted our first series of four professional development webinars for educators. Equipped with the knowledge of how to support students with TS, these educators will work to destigmatize TS and create an accessible education environment for kids with tics.

For more than 20 years, the TAA has been training service providers on a protocol for the non-medical treatment of tics, called Comprehensive Behavioral Intervention for Tics (CBIT). Developed by TAA researchers, CBIT is a nationally recognized first-line treatment for TS and Tic Disorders that can provide valuable relief to those whose lives are affected by this complex condition. This year, the TAA trained 719 professionals in CBIT so they can help patients effectively reduce tic severity. These training and technical assistance accomplishments are broadening the scope of knowledge on Tourette Syndrome and ensuring that people who may not even realize that there is a name for their condition find the help they need.

**Youth and Young Adult Development**

Because Tourette Syndrome most often manifests in childhood, it is crucial that the TAA reaches young people to ensure that they have the best possible understanding of their condition and the ability to advocate for themselves in their classrooms, workplaces, and communities. Without the resources and support that the TAA provides, a child or young person might feel overwhelmed and disheartened when trying to explain to their peers what tics are or why they cannot “just stop doing that.” To position young people with TS for lifelong success, the TAA puts a focus on reaching and teaching as many as possible.

The Youth Ambassador and Rising Leader programs at the TAA are the only programs of their kind that teach youth and young adults affected

“I am now serving as a Rising Leader for the Tourette Association. Finally, Tourette has granted me opportunities to be an advocate, a mentor, and an example to my community and the Tourette community.”

—Emberly
by TS, up to the age of 25, to become champions for themselves and the TS community. We trained 78 young people this year, who went on to give presentations in their schools and communities and speak to local media and lawmakers about their experiences with Tourette Syndrome. By providing young people with a platform to advocate for themselves and their peers, the TAA is ensuring young people with TS have invaluable opportunities to increase their confidence. After graduating from our programs, they go on to become incredible advocates for our mission for the rest of their lives.

Research and Medical

Integral to the TAA’s mission to make life better for the TS and Tic Disorders community is our commitment to advancing scientific research. Our understanding of the medical needs of people with Tourette Syndrome continues to change as we learn more about the condition, and we continue to adapt our Research and Medical program to meet these needs.

The feedback we receive from our community is our most valuable tool in assessing the needs and direction for our programs. From December 2021 to January 2022, we conducted a web-based survey among our community to ask about their experiences with TS and Tic Disorders. Almost 1,200 people, both adults and children, participated in the survey, which was an unprecedented response. Through this impact survey, we heard firsthand about the most significant issues facing our community, including the need to focus on providing comprehensive mental healthcare. With this new eye-opening information, we are better equipped to advocate on behalf of our community.

The focus of Research and Medical, one of our longest standing programs, is preparing the next generation of researchers to discover innovative
solutions to the TS community’s needs. Through our Young Investigator Awards, we granted five early career researchers $747,000 overall, to fund their efforts for improving a biological understanding of Tourette Syndrome, advancing patient care, and developing new therapies. We also expanded our Centers of Excellence, which recognize medical institutions that offer the highest level of care and are leaders in the field. With the addition of the Ann & Robert H. Lurie Children’s Hospital of Chicago Tourette Center of Excellence, the Texas Children’s Pediatric Movement Disorders Clinic, and the Vanderbilt Center for Tourette Syndrome and Other Tic Disorders, we now have 21 Centers of Excellence nationwide. These partners are undertaking groundbreaking research and providing exceptional community outreach and advocacy for our community.

Public Policy

The civil rights of people with Tourette Syndrome and other disabilities are the subject of a constant struggle in our country. Great strides have been made, but only as the result of dedication and persistence by committed disability advocates. We lobbied for progressive legislation, including continued coverage for telehealth services after the end of the Public Health Emergency for COVID-19 and improved appeals processes for step therapy, which is a very restrictive and at times dangerous form of utilization management by Prescription Benefit Managers. In Congress, a record 103 bipartisan representatives and 25 senators signed letters of support for continued funding of the CDC’s Tourette Syndrome Program.

For our annual Advocacy Day, which was held virtually, the TAA provided an opportunity for our Youth Ambassadors and Rising Leaders to have their voices heard on Capitol Hill in Washington, D.C. More than 250 attendees

“As a Youth Ambassador, I had the opportunity to lobby for funding and awareness in Washington D.C. I have used the resources and things I learned from that trip to speak in front of classes and educate others.

—Arianna
from 38 states sent letters and held meetings with lawmakers, resulting in more than 3,000 impressions and doubling the number from last year. The TAA is proud to raise the voices of our often-unheard community members at the highest levels of government to ensure that people with disabilities are no longer left behind.

**Pilot Neurodiverse Workforce Development Initiative**

Our Neurodiverse Workforce Development Program provides adults impacted by TS, Tic Disorders, and related disabilities with the tools they need to thrive in the workplace. We also educate employers about the needs of the neurodiverse community and the advantages of a workforce that includes those who are neurodiverse. Through this program, the TAA provides mock interview opportunities, resume writing workshops and other resources to neurodivergent people who are seeking employment or workplace assistance. More than 75 percent of mock interview participants found the experience to be helpful preparation for future interviews, and 83 percent considered the feedback provided by their interviewer to be extremely helpful. In partnership with Oracle, the TAA also hosted the first Neurodiverse Workforce Development Summit. This program is not limited to people with Tourette Syndrome, as we recognize that all neurodivergent people face struggles in the workplace and that to advocate for the entire community is the best way to make sure no one with any disability is left behind.

“Learning about neurodiversity is a journey. It is important to position neurodiversity in terms of strengths and skills, rather than as deficits and disabilities.” —Neurodiversity in the Workplace: A Summit hosted by the TAA in partnership with Oracle Corporation. TAA Neurodiversity Report 2022
FINANCIAL STEWARDSHIP

YOUR TAA DOLLARS AT WORK
BASED ON AUDITED FINANCIALS FOR FISCAL YEAR ENDED FEBRUARY 28, 2022

OVERVIEW:
Total FY 2022 revenue of $4,561,570
Total FY 2022 expenses of $4,222,801
Overall surplus for FY 2022 of $338,769

Expense breakdown

Program:
Public Education . . . . . . . . . . . . . . . . . . $1,592,629
Professional Education . . . . . . . . . . . . . . . . . 19,024
Federal Funding . . . . . . . . . . . . . . . . . . . . . 868,247
Research . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .772,778

Total Program . . . . . . . . . . . . . . . . . . . . . . . . . . . . . 3,252,678

Administrative:
Management & General . . . . . . . . . . . . . . 508,320
Fundraising . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .461,803

Total Administrative expenses . . . . . . . . . . . . . . . . . .970,123

Total expenses . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .4,222,801
### TOURETTE ASSOCIATION OF AMERICA INC.
### STATEMENTS OF FINANCIAL POSITION
### AS OF FEBRUARY 28, 2022 AND 2021

<table>
<thead>
<tr>
<th></th>
<th>2022</th>
<th>2021</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASSETS</td>
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<tr>
<td>Cash and cash equivalents</td>
<td>98,354</td>
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<td>Grants receivable</td>
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<td>Contributions receivable, net</td>
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<td>Investments</td>
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<td>334,000</td>
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<tr>
<td>Investments - permanently restricted</td>
<td>173,942</td>
<td>144,825</td>
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<td>Prepaid expenses and other assets</td>
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<td>35,159</td>
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<td>Property and equipment, net</td>
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<tr>
<td><strong>TOTAL ASSETS</strong></td>
<td>11,736,131</td>
<td>11,623,666</td>
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<tr>
<td>LIABILITIES</td>
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<tr>
<td>Accounts payable and accrued expenses</td>
<td>284,352</td>
<td>181,452</td>
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<td>Research grants payable</td>
<td>1,151,316</td>
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<tr>
<td>Refundable advance</td>
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<td>395,177</td>
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<tr>
<td>Deferred revenue</td>
<td>19,702</td>
<td>25,992</td>
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<tr>
<td><strong>TOTAL LIABILITIES</strong></td>
<td>1,455,370</td>
<td>1,681,674</td>
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<td>COMMITMENTS AND CONTINGENCIES</td>
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<tr>
<td>NET ASSETS</td>
<td></td>
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<tr>
<td>Without Donor Restrictions</td>
<td>9,063,123</td>
<td>8,539,124</td>
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<tr>
<td>With Donor Restrictions:</td>
<td></td>
<td></td>
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<tr>
<td>Restricted for time and purpose</td>
<td>743,638</td>
<td>1,068,868</td>
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<tr>
<td>Perpetual in nature</td>
<td>474,000</td>
<td>334,000</td>
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<tr>
<td><strong>Total net assets with donor restrictions</strong></td>
<td>1,217,638</td>
<td>1,402,868</td>
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<tr>
<td><strong>TOTAL NET ASSETS</strong></td>
<td>10,280,761</td>
<td>9,941,992</td>
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<tr>
<td><strong>TOTAL LIABILITIES AND NET ASSETS</strong></td>
<td>11,736,131</td>
<td>11,623,666</td>
</tr>
</tbody>
</table>
# Tourette Association of America Inc. Statements of Activities
## For the Years Ended February 28, 2022 and 2021

## Support and Revenue:

<table>
<thead>
<tr>
<th>Category</th>
<th>2022</th>
<th>2021</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Public Support:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fund raising events revenue</td>
<td>$980,154</td>
<td>$831,818</td>
</tr>
<tr>
<td>Less: direct benefits to donors</td>
<td>(150,441)</td>
<td>(32,766)</td>
</tr>
<tr>
<td>Net fundraising events revenue</td>
<td>829,713</td>
<td>799,052</td>
</tr>
<tr>
<td>Grants, contributions and bequests</td>
<td>2,442,129</td>
<td>2,097,353</td>
</tr>
<tr>
<td>Membership dues</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total Public Support</strong></td>
<td>3,271,842</td>
<td>2,896,405</td>
</tr>
<tr>
<td><strong>Government Support:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C.D.C. grant</td>
<td>868,158</td>
<td>773,298</td>
</tr>
<tr>
<td><strong>Total Government Support</strong></td>
<td>868,158</td>
<td>773,298</td>
</tr>
<tr>
<td><strong>Revenue:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Investment activity</td>
<td>354,035</td>
<td>960,088</td>
</tr>
<tr>
<td>Sales - emblems, audio visuals and publications</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Conference income</td>
<td>67,535</td>
<td>109,853</td>
</tr>
<tr>
<td><strong>Total Revenue</strong></td>
<td>421,570</td>
<td>1,069,941</td>
</tr>
<tr>
<td><strong>Total Support and Revenue</strong></td>
<td>4,561,570</td>
<td>4,739,644</td>
</tr>
</tbody>
</table>

## Expenses:

<table>
<thead>
<tr>
<th>Category</th>
<th>2022</th>
<th>2021</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program services</td>
<td>3,252,678</td>
<td>3,465,058</td>
</tr>
<tr>
<td>Management and general</td>
<td>508,320</td>
<td>543,123</td>
</tr>
<tr>
<td>Fundraising</td>
<td>461,803</td>
<td>508,677</td>
</tr>
<tr>
<td><strong>Total Expenses</strong></td>
<td>4,222,801</td>
<td>4,516,858</td>
</tr>
</tbody>
</table>

## Change in Net Assets:

<table>
<thead>
<tr>
<th>Category</th>
<th>2022</th>
<th>2021</th>
</tr>
</thead>
<tbody>
<tr>
<td>Net assets - beginning of year</td>
<td>9,941,992</td>
<td>9,719,206</td>
</tr>
<tr>
<td><strong>Net Assets - End of Year</strong></td>
<td><strong>$10,280,761</strong></td>
<td><strong>$9,941,992</strong></td>
</tr>
</tbody>
</table>
DONOR RECOGNITION

Our work would not be possible without people like you. Thanks to your generous support, we can continue making our community stronger. Thank you!

$100,000+:  
Emalex Biosciences, Inc  
Estate of Alfred Enisz  
Ken and Julie Moelis  
The Moelis Family Foundation  
The Ochsman Foundation Inc.  
Derek and Ashley Ramsey  
Elaine Wanderer  
Zemsky Family Foundation

$10,000 - $24,999:  
Reid Ashinoff  
The Asness Family Foundation  
Debbie & Mark Attanasio  
Stephen and Carol Barron  
John Barto, Jr.  
Marc Benson  
The Blackbaud Giving Fund  
Joseph Bonasera  
Hannah Branch  
Louis and Julie Bucksbaum  
Community Mediation Services Inc.  
Frederic and Sharon Cook  
David and Jeanine Davies  
The Geaton & JoAnn DeCesaris Family Foundation  
Lori Del Vecchio  
Endaoment  
Fieldstead & Company  
John Fogelman  
Foundation 214  
Frankle Family Foundation  
Jerry Gidner  
Jeanne and H. Thomas Gnuse  
Peter J. Hollenbeck  
The Jansen and Janson Families  
Brian Kwait

$50,000 - $99,999:  
Boston Scientific Corporation  
Darryl and Diane Mallah  
Otsuka Pharmaceutical Development & Commercializatin, Inc.  
Warren & Katherine Schlinger Foundation

$25,000 - $49,999:  
Ronald W.Burkle  
Dentons US LLP  
Paul and Anne Devore  
John C. Dunphy Private Foundation, Inc.  
Ghada & Ray Irani  
Johnson & Johnson  
Monte N. Redman  
Leon M. Wagner  
Helene B. Walisever
Steven Lebow
National Philanthropic Trust
Nelson Family Foundation
New Canaan Community Foundation
Billie O’Connell
Ressler/Gertz Family Foundation
Marc J. Rowan
David A. Sachs
Rovena and Robert Schirling
Singer Family Foundation
Patricia and George Sistrunk
Jane Smolik
Jonathan D. Sokoloff
Jasmine and Robert Tarkoff
The Travelers Companies, Inc.
The Joseph Leroy and Ann Warner Fund, Inc.
Stuart and Jane Weitzman
Wishnow, Ross, Warsavsky & Company
Alisa Yaffa

$5,000 - $9,999:
Warren Alpert Foundation
American Legion Child Welfare Foundation
Frank J. Antun Foundation
Michael and Margot Benstock
Community Health Charities of America
Susan and Mark Courey
Elizabeth Crain
Crescent Capital Group LP
David Fox
William Hankinson
Thomas Hopkins
The Huisking Foundation Inc
Investors Foundation, Inc
Richard and Joan Jordan
Cindy and Brad Kurtz
Ronald & Kirstin Lamb Charitable Giving Fund
Rick Leaman
M & T Charitable Foundation
Dave Mahoney
Charles and Robin Malk
Barry Malkin
Mutual of America
Marcy Newberger
Finneas O’Connell
Sue Pearl
Jeff Raich
Stewart and Lynda Resnick
J H Tarter & J Tefft Tarter Rev Trust
John T. Walkup
Dorothy Waugh Charitable Trust

$1,000 - $4,999:
Acadia Pharmaceuticals
John Allison
Suzanne Allswang
Robert Alpert
AmazonSmile Foundation
James E. Ames IV
Azad Anand
Charles J. Anteby
Rhonda L. Ashinoff
The Baldwin Family
Gail Regenbogen
John D. Reyna, Jr.
John R. Roesset
Rebecca Rothstein
Rothstein Family Donor Advisory Fund
Manuel Ruiz
David T. Rusoff
Sablosky Family Foundation
Olivier Sarkozy
Helen and Moshe Sassover
Budd Scheffler
Dennis Schneider
Stacey Schneider
Thomas V. Schneider
David R. R. Schoenhaar
Kristy Schworm
Jane Seder
Karen L. Segall
David Seligman
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Steve Serck
Kyle Shoemaker
Howard Silberstein
William R. Smith
Gayle and Steve Solk
Kate Solomon
William Spiry
Ben Sprecher
Greg and Lesa Starkins
Harvey Steinhoff
Carolyn Stone
Shih-ping Sun
Howard Swibel
Steven Swidler
Elizabeth Syfert
Samuel Tesauro
Christopher Tosheff
James Turner
Dave Turville
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Marci and Rudy Valner
Jennifer and John M. Vargas
Victory Wholesale Group
Pamela Welly and Dorothy Synder
Jamie Wiley
Karon Williams
Brad Wiss
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Roger Wood
Richard A. Zellmer
Don and Lavonne Zietlow
Ronna and Steven Zoll
Richard Zuckerman
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Sonja Mason-Vidal, Vice President, Finance and Administration
Karon Williams, Vice President, Resource Development,
   Marketing and Affiliate Services