



2017 - 2018

Sponsorship
Opportunities





The RareVoice Awards is an annual celebration to honor advocates who give rare disease patients a voice on Capitol Hill. Patient advocates, industry executives, and congressional and government agency staff gather to honor these outstanding advocates for the rare disease community.

Tickets are complimentary for the general public, members of Congress, Congressional and governmental staff.

Proceeds from the RareVoice Awards event go toward supporting Rare Disease Legislative Advocates (RDLA).

RDLA is a program of the EveryLife Foundation for Rare Diseases designed to support the advocacy of all rare disease patients and organizations. By growing the patient advocacy community and working collectively, we can amplify our many voices to ensure that rare disease patients are heard in state and federal government.

RDLA provides free resources for successful grassroots advocacy and serves as a clearinghouse of ideas that is open to all members of the rare disease community with an interest in sharing information around common causes and advocating for the introduction or enactment of legislation.

The 6th Annual RareVoice Awards November 15, 2017 Arena Stage Washington, D.C.

6:00 p.m. Cocktail Reception

6:30 p.m. Congressional Toast

8:00 p.m. Awards Ceremony

9:00 p.m. After Party Celebration



Past Awards

In its 6th year, the RareVoice Awards is RDLA's signature annual celebration to honor those whose advocacy for legislation has raised the "voice" of the rare disease community at the federal and state level. This is a widely attended, free public event for patient advocates, congressional and government agency staff and industry to celebrate the accomplishments of the honorees.

Award recipients are chosen by committee from nominations received from the rare disease community. Honorees receive an "Abbey" statuette, named for Abbey Meyers, founder of the National Organization for Rare Disorders (NORD). Past recipients of the Abbey include:

Lifetime Achievement

2012 Abbey Meyers

2013 Patricia Furlong

2014 Stephen Groft, Pharm.D

2015 Hon. Fred Upton

2016 Hon. Orrin Hatch

2016 Ronald Bartek



Congressional Leadership

2012 Hon. Michael McCall

2012 Hon. Cliff Stearns

2013 Hon. Michael Burgess, MD

2013 Illeana Ros-Lehtinem

2014 Hon. David McKinley, PE

2014 Hon. Doris Matsui

2015 Hon. Gus Billirakis

2015 Hon. GK Butterfield

2015 Hon. Diana DeGette

2016 Hon. Joseph Crowley

2016 Hon. Lamar Alexander

State Legislator

2016 Richard Pan, MD



Congressional Staff

2012 Thomas Power

2012 Emily Shetty

2012 Andy Taylor

2013 Art Estopinan

2014 Cheryl Jaeger

2015 Saul Hernandez

2015 Clay Aspach

2016 Grace Stuntz

Past Awards

Federal Agency

- 2013 Mike Asture
- 2013 Janet Woodcock, MD
- 2014 Allen E. Guttmacher, MD
- 2015 William A. Gahl, MD, PhD
- 2016 John Gallin, MD



Federal Patient Advocacy

- 2012 Nancy Goodman
- 2012 Roy Zeighami
- 2013 Jill Wood
- 2014 National Down
- 2014 Gabriella Miller
- 2015 Lisa & Max Schill
- 2016 David Fajgenbaum, MD

Special Presentation/ Patient Advocate

- 2012 Mark Dant
- 2013 John F. Crowley, JD, MBA
- 2014 Jonny Lee Miller



State Patient Advocacy

- 2014 Jeff Leider
- 2015 Patricia Weltin
- 2016 Gina Szajnok
- 2016 Sabrina Low-DuMound





2017 - 2018

Sponsorship Opportunities

As an industry sponsor of RareVoice, you are supporting our work to educate rare disease advocates about how legislation and policy impact the availability and access to treatments and to provide the necessary resources to be successful legislative advocates. The proceeds from the RareVoice Awards also benefits our advocacy programs offered during Rare Disease Week on Capitol Hill.

Support from our industry partners has been critical to our progress, but there is still significant work to be done and we greatly appreciate your consideration of support of the RareVoice Awards.



Sponsorship Opportunities

SPONSORSHIP LEVEL		PRESIDENTIAL	ABBEY	PLATINUM	GOLD	SILVER
DONATION		SOLD \$80,000	\$50,000	\$35,000	\$20,000	\$15,000
RESERVED AWARDS PROGRAM GUEST SEATING 		10 GUESTS	10 GUESTS	6 GUESTS	4 GUESTS	
RESERVED COCKTAIL RECEPTION GUEST SEATING 		10 GUESTS	10 GUESTS	4 GUESTS	2 GUESTS	
LOGO ON WEBSITE, EVENT SIGNAGE, INVITATIONS AND COMMUNICATIONS 		PREMIUM	PREMIUM	STANDARD	STANDARD	STANDARD
LOGO ON COCKTAIL NAPKINS 				INCLUDED		
EXCLUSIVE LOGO ON STEP AND REPEAT 		INCLUDED				
POST AWARD CEREMONY RECEPTION SPONSOR 			INCLUDED			
CONGRESSIONAL TOAST INTRODUCTION SPEAKER 			INCLUDED			
AWARDS CEREMONY GUEST SPEAKER 		INCLUDED				
DJ SPONSOR WITH SHOUT OUT 				INCLUDED		
SPONSOR AD IN PROGRAM BOOK 		FULL PAGE	FULL PAGE	FULL PAGE	HALF PAGE	QUARTER PAGE
LOGO IN POLITICO EVENT ADVERTISEMENT 		INCLUDED	INCLUDED	INCLUDED	INCLUDED	INCLUDED
SOCIAL MEDIA RECOGNITION 		3 TO 4 MENTIONS	2 TO 3 MENTIONS	2 MENTIONS	1 MENTION	1 MENTION

Making an Impact

We strive to make an impact and are truly grateful to have a wonderful team of sponsors, organizations, award recipients, professional leaders and advocates who work with us to accelerate the process to finding cures.

Pat Furong

Founding President and CEO of Parent Project Muscular Dystrophy (PPMD)

“Receiving the Rare Voice Award was incredible because it felt like it was a tribute to my sons, that their lives mattered and a tribute to all those who follow in their footsteps. One of the many things I love about the EveryLife Foundation are the people – they are changing the world by connecting people who are committed to make a difference.”

David Fajgenbaum, MD, MBA, MSc

**Asst. Prof. of Medicine, University of Pennsylvania
Assoc. Dir., Penn Orphan Disease Center
Exec. Dir., Castleman Disease Collaborative Network**

“As a rare disease patient and physician-scientist, I have been amazed by the incredible work that the EveryLife Foundation, RDLA, and the winners of the RareVoice awards do to accelerate the development of life-saving therapies. They give me hope for my future and the future for so many others with rare diseases. I was so honored to receive the RareVoice award last year among the hundreds of other rare disease patients and loved ones who fight alongside me and deserve the award just as much as I.”

Jill Wood

Co-Founder Jonah's Just Begun

“What makes the RareVoice Awards so special is that our rare disease community votes on it. People we admire and look up to. I have taken inspiration from honorees before me and I am sure it will continue to inspire advocates to get work done.”

Sabrina Low-Dumond

Parent Advocate

“Whether you're participating in a clinical trial, serving on a patient advisory board, starting a patient organization or volunteering, your 'voice' is moving the rare disease community forward and that is what is important.”



RARE VOICE

Awards

Headquarters: 77 Digital Drive, Suite 210 • Novato, CA 94949

Office: (415) 884-0223

440 First Street Northwest, Suite 430 • Washington, DC • 20001

(202) 697-RARE(7273) • rareadvocates.org/rarevoice-awards

#RareVoiceAwards  

