



## 2019 SPONSORSHIP OPPORTUNITIES



For sponsorship opportunities, contact:  
**Jaime Pacheco**, Development and Events Associate | 203.744.0100 | [jpacheco@rarediseases.org](mailto:jpacheco@rarediseases.org)

**#RUNNING4RARE** | [runningforrare.org](http://runningforrare.org)



## What Is a Rare Disease?

*Any disease, disorder, illness or condition affecting fewer than 200,000 people in the United States is considered rare.<sup>1</sup>*

It is estimated that 25-30 million Americans live with rare diseases. There are approximately 7,000 rare diseases, more than 90 percent of which are without an FDA-approved treatment.

## The National Organization for Rare Disorders

For many years, people with rare diseases walked alone. Patients and their families coped with daunting medical and financial issues with few resources and no one to guide the way. Then, a small group of patient advocates formed a coalition to unify this community and mobilize support to pass the Orphan Drug Act.

In 1983, that coalition became NORD, the National Organization for Rare Disorders. For more than 35 years, NORD has led the way in voicing the needs of the rare disease community, driving supportive policies, advancing medical research and providing patient and family services for those who need it most.

*For over 35 years, NORD has been providing services for patients and their families, rare disease patient organizations, medical professionals, and those seeking to develop new diagnostics tools and treatments.*

*We are here to support every member of the rare disease community with programs and services focused on one ultimate goal:*

*To improve the lives of individuals and families affected by rare diseases.*



#RUNNING4RARE

# NORD's Charity Running Team

NORD's Running for Rare Team has formed a community partnership with runners and patients to raise awareness for rare and undiagnosed diseases, form patient connections and provide a forum for emotional support for those undergoing similar medical challenges.

This grassroots team has grown to unite over 200 runners and patients, raising more than \$1,500,000 over the last twelve years. When participants become part of the Running for Rare Team, they are joining a group of individuals who are passionate and committed to an important cause. As any past team member will tell you, being part of this team is a unique, life-changing experience.

## Rare Community Partners

What makes this team so unique is the Rare Community Partner program. Each runner is paired with a partner (patient, family, advocate or other) and together they build a relationship throughout the runner's training and marathon race.



This pairing is the foundation for inspiration that propels runners through training and race day. The partnerships are more than symbolic. They are the beating heart of the team, and the Rare Community Partners are as much members of the team as the runners.

This program also gives each partner a platform to tell their story, raise awareness, find support and connect with others going through similar challenges.



*"Although our goal was to run the marathon, which was an amazing experience in of itself; the journey involved the team training, patient partner interactions and fundraising, which together made the experience worthwhile!"*

– Running for Rare Team Member



#RUNNING4RARE

# Running for Rare's Signature Races

## 2019 TCS New York City Marathon Sunday, November 3, 2019

The Marathon has always been an exercise in community spirit, especially after September 11, 2001. This race continues to remain a symbol of hope and renewal for participants, spectators, and all New Yorkers. NORD is grateful to have been selected as an official charity for the third year in a row.



*"Having this shared experience renewed my confidence that we really are all in a better position if we can work together for common goals. The level of commitment and passion demonstrated by the team was inspiring!"*

– 2018 Running for Rare Boston Marathon Team Member

## 2019 Boston Marathon Monday, April 15, 2019

The Boston Marathon is the world's oldest annual marathon and ranks as one of the world's most prestigious road racing events. NORD has 13 runners and 15 community partners on this year's Running for Rare Boston Marathon Team.



# Running for Rare's Satellite Programs

Through the satellite program, runners from across the globe are welcome to join NORD's Running for Rare team in any race of their choosing – marathon, 5K, cycling, walking, climbing or even an Iron Man, all while raising funds for rare and undiagnosed diseases. Runners can choose to participate in an event solo or create a team. Based on a runner's fundraising commitment, the satellite program offers a variety of benefits including:

- Fundraising Page
- Personalized Fundraising Advice
- Access to Training Plans
- Team Singlet



#RUNNING4RARE

# Sponsorship

As a 501(c)(3) charity, we need your support to ensure that this vital community-building program is sustained. Program sponsorship helps to offset the purchase of bibs for signature races, team shirts and singlets, team dinners and promotional items for each participant. Your sponsorship will allow monies raised by each team to go directly to patients with rare and undiagnosed diseases.

## Exclusive Sponsorship Opportunities

### Sponsors Receive:

- Attendance and brand recognition at signature race team dinners
- Attendance and brand recognition at team post-race reception in Boston
- Logo featured on team singlets and shirts\*\*
- Logo featured on Running for Rare website
- Logo featured on race day signage
- Social media mention on Running for Rare Facebook page

*\*\*If received 90-days before race-day*

### Donation Levels:

#### A donation of \$50,000 supports:

- 20 community partners to participate in signature races
- 15 signature race runners
- Runner resources and networking tools
- 2 satellite race teams

#### A donation of \$25,000 supports:

- 10 community partners to participate in signature races
- 7 signature race runners
- Runner resources and networking tools

#### A donation of \$10,000 supports:

- 5 community partners to participate in signature races
- 3 signature race runners



To book your sponsorship or for more information, please contact:

**Jaime Pacheco**, Development and Events Associate | 203.744.0100 | [jpacheco@rarediseases.org](mailto:jpacheco@rarediseases.org)

©2019 NORD. All rights reserved. NORD, its logo and Running for Rare are registered trademarks of The National Organization for Rare Disorders. NORD is a registered 501(c)(3) organization. NORD provides this information for the benefit of the rare disease community. NORD is not a medical provider or health care facility and thus can neither diagnose any disease or disorder nor endorse or recommend any specific medical treatments. Patients must rely on the personal and individualized medical advice of their qualified health care professionals before seeking any information related to their particular diagnosis, cure or treatment of a condition or disorder. NRD-1169