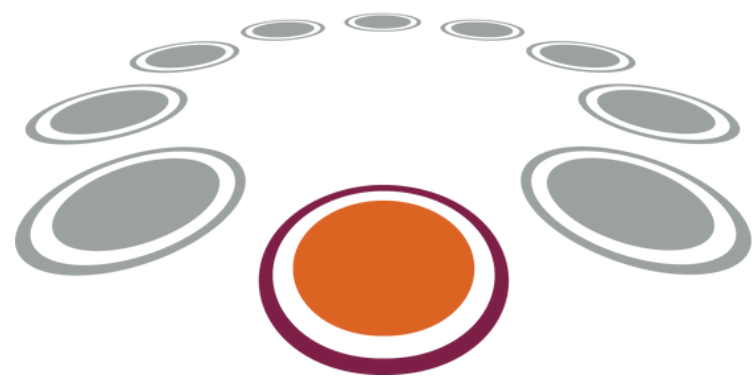


# Nano-rare Patient Colloquium 2024



**October 30-31, 2024**

Cambridge, Massachusetts

**Boston Marriott Cambridge**

Hosted by:  **Biogen**



# LOCATION

## Check-in / Location

**Boston Marriott Cambridge**  
**50 Broadway, Cambridge, MA 02142**

- Attendees will receive a badge upon check-in
- It is preferred that attendees [register](#) in advance



## Parking

**Boston Marriott Cambridge**  
50 Broadway, Cambridge, MA 02142  
(617) 494-6600

Valet  
Daily .....\$58.00

**VPNE Parking Kendall Center**  
90 Broadway St., Cambridge, MA 02142  
(617) 621-7618

0 - 1 hour.....\$18.00  
1 - 3 hours.....\$38.00  
Max Daily Rate.....\$48.00



# Nano-rare Patient Colloquium 2024

CONTACT US

9410 Carroll Park Dr,  
San Diego, CA 92121

760-378-8001  
[www.nlorem.org](http://www.nlorem.org)

Hosted by:  **Biogen**<sup>®</sup>





# TRAVEL

## Airport

**Boston Logan Intl**  
1 Harborside Dr East  
Boston, MA 02128  
800-235-6426

## Taxi/ Ride Share

At Boston Logan Intl,  
Arrivals level at Terminals  
A, B, C & E  
Taxi Phone: 617-499-4800

## Transportation

Ride share estimate: \$40  
Rental cars: **(for 30 % off)**  
Budget: BCD code V103988  
Avis: AWD code W625346

\*\*As a non-profit focused solely on helping our nano-rare patients, n-Lorem has limited funding. However, if you require funding for travel, please contact Nafiso Hussein at [nafiso.hussein@nlorem.org](mailto:nafiso.hussein@nlorem.org)

## Boston Marriott Cambridge

50 Broadway,  
Cambridge, MA 02142  
(617) 494-6600

[Click to book](#)



## The Royal Sonesta Boston

40 Edwin H Land Blvd,  
Cambridge, MA 02142  
(617) 806-4200

1.2 miles away from Boston Marriott Cambridge

[Click to book](#)



## Residence Inn by Marriott

120 Broadway, Cambridge, MA 02142  
(617) 349-0700

0.1 miles away from Boston Marriott Cambridge

[Click to book](#)



# Nano-rare Patient Colloquium 2024

CONTACT US

9410 Carroll Park Dr,  
San Diego, CA 92121

760-378-8001  
[www.nlorem.org](http://www.nlorem.org)

Hosted by:  **Biogen**<sup>®</sup>





# TRAVEL

Tip: Discounted rates available for hotel members

## Homewood Suites

1 Massachusetts Ave., Arlington,  
MA 02474

(781) 643-7258

4.1 miles away from Boston Marriott Cambridge

[Click to book](#)



## Cambria Hotel Boston Somerville

515 Somerville Ave., Somerville,  
MA 02143

(833) 577-7106

2.0 miles away from Boston Marriott Cambridge

[Click to book](#)



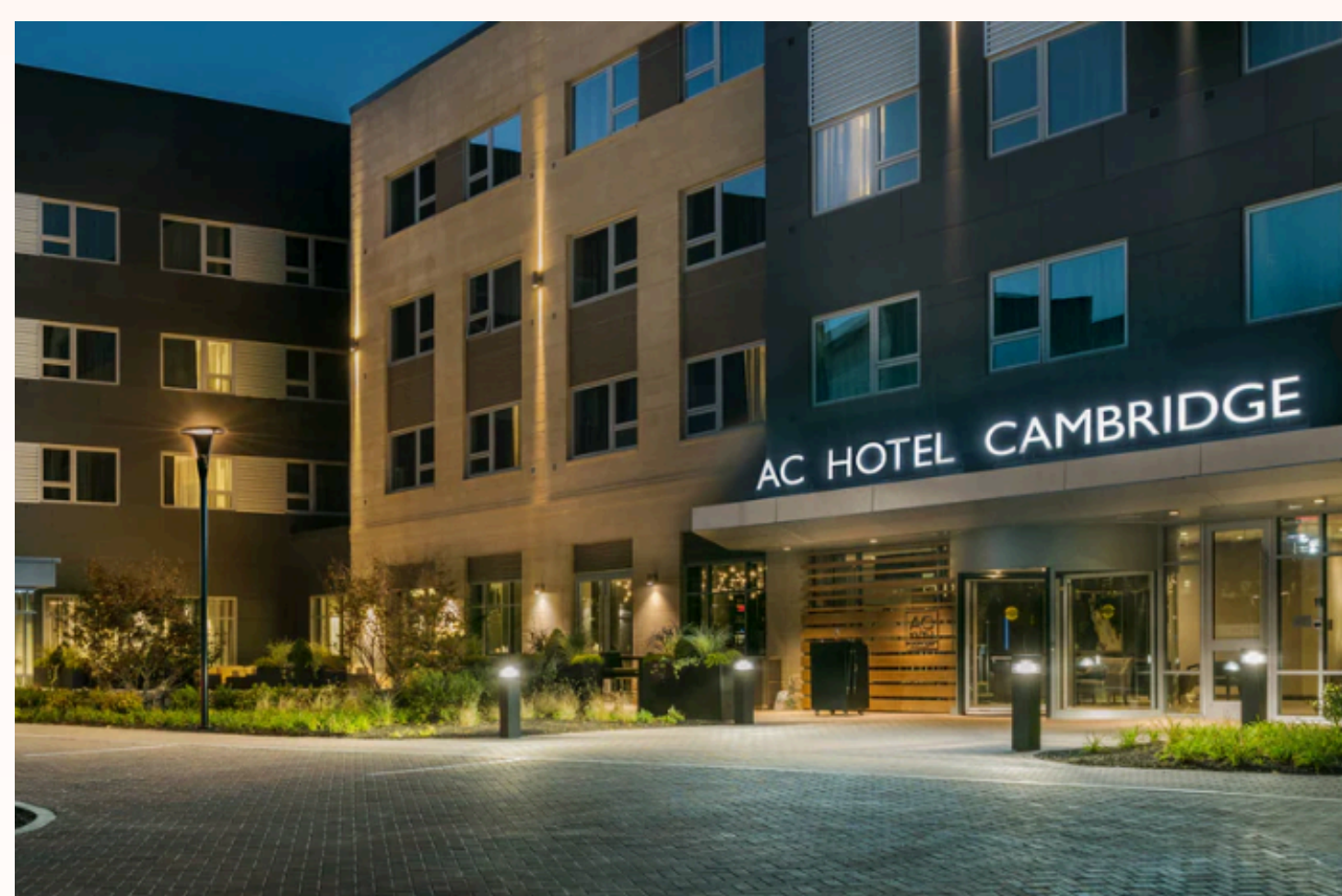
## AC Hotel Boston Cambridge

10 Acorn Park Drive Cambridge,  
MA, 02140

(617) 876-6190

4.6 miles away from Boston Marriott Cambridge

[Click to book](#)



## Hilton Garden Inn Brookline

700 Brookline Ave., Brookline,  
MA 02446

(617) 935-0077

3.6 miles away from Boston Marriott Cambridge

[Click to book](#)



## Nano-rare Patient Colloquium 2024



CONTACT US

9410 Carroll Park Dr,  
San Diego, CA 92121

760-378-8001  
[www.nlorem.org](http://www.nlorem.org)

Hosted by:



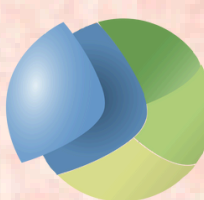




# 2024 Nano-rare Patient Colloquium

October 30-31, 2024 | Cambridge, MA

## AGENDA

Hosted by:  **Biogen**



### **Panel: Hope realized; the culmination of effort, perseverance and belief in a better outcome**

Our pioneering patients are paving a pathway for more nano-rare patients, providing valuable information on health and disease and experiencing, for the first time, targeted therapeutic intervention for their genetic conditions. Please join us as we hear their diagnostic stories from the patients and their families. We will follow these with case reports on these patient's clinical experiences presented by the physicians who are so committed to caring for these patients. This panel will feature four different patient/physician interviews that will be conducted by Brady Huggett and will be dispersed throughout the day and a half event.

### **Panel: What it means go be a partner with n-Lorem for nano-rare**

The challenges presented by nano-rare patients are far too complex for n-Lorem to solve even a fraction of the issues without support. Thus, our goal from inception has been to build as broad and effective a network of contributing stakeholders. In this panel, our partners in our community of care discuss what it means to be a partner with n-Lorem, including how partnering with n-Lorem provides their employees with a feeling of purpose and what more their organization can do to support nano-rare. This panel will feature executives from n-Lorem partners and supporters who believe in the mission and are committed to helping n-Lorem reach even more patients.

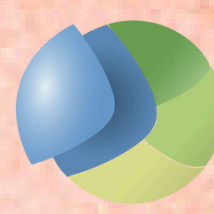
### **Panel: Building a nano-rare network and managing institutional challenges**

Creating, developing and providing an individualized/personalized ASO medicine for an individual patient is only part of the challenge that faces n-Lorem and our patients today. Our physicians and institutional partners are key to ensure that not only are our patients cared for, but that they can access the treatments we offer. We are continually expanding our network to bring more physician and institutional partners together to work with us in getting our nano-rare patients the treatments that could change their lives. This panel will include physicians from across the US to discuss their unique challenges and some of the innovative ways they have garnered institutional support for their patients.



# 2024 Nano-rare Patient Colloquium

## AGENDA cont.

Hosted by:  **Biogen**



### **Panel: Innovative ways to support nano-rare**

As n-Lorem scales to meet an ever-growing demand, new challenges arise. Many of these challenges will take innovative solutions and support from leaders and experts in a variety of different fields. Together as a community, we are creating a path forward for nano-rare patients and changing the way that genetic diseases are treated. This panel brings together leaders and experts in areas where significant challenges exist to brainstorm how to overcome these challenges and advance treatments for even more nano-rare patients.

### **Panel: The perilous journey to diagnosis and treatment for nano-rare patients**

This panel is back by popular demand. n-Lorem exists to serve the nano-rare patient community. The opportunity for ASO treatment provides hope to the hopeless and eventually, we hope, treatments for many. Hopelessness and despair that come at the end of a long and perilous journey to diagnosis are devastating. In this special panel, some of our nano-rare patients share their diagnostic odysseys and what n-Lorem means for them. We will meet and learn about more nano-rare patient journeys to n-Lorem and the hope that n-Lorem brings to them and their families.

### **Panel: Changing the world one patient at a time**

At the onset, we wanted to engage renowned leaders in their fields to provide expert guidance as we navigate new territory, nano-rare. We believe that every patient deserves to have the best minds coming together to help them. Our experts donate their time, their expertise and their insight for our patients and help us by serving on a number of committees that provide expert advice and guidance across all steps of the treatment pathway. In this panel, our experts sit down to discuss why they believe in n-Lorem and together how we are truly changing the world one patient at a time.

*and more!*

**Additional presentations from physicians, experts,  
and n-Lorem staff to be announced later**