



Greetings!

I hope you are enjoying the warm summer months. It was great seeing so many friendly faces, recently, at our second annual Power in Community Conference. Thank you to our great sponsors. We are already planning for next year's event.

Our research is gaining momentum and we've recently brought on two new partners to get us to clinic – Charles River Labs, whose experience in regulatory affairs is unparalleled, along with Nationwide Children's Hospital, who is a leader in AAV production (viral delivery vector for our therapeutic). We are excited to be making strong progress and have recently enrolled additional boys in the customized medicine process. To continue the process, we have a few events planned to help with funding: **Ride to Cure Rare Disease on September 21st on Cape Cod** along with our **third annual gala on October 24th at the Boston Wyndham Beacon Hill**.

Below, you'll find the updates of our newsletter.

All the best,

-Rich Horgan
Founder & President

CRD Ride to Cure Rare Disease - South Yarmouth Saturday, September 21st, 2019

Ride to Cure Rare Disease is a bike ride fundraiser, not a race, which brings together riders from all walks of life united in the mission to end rare disease as they ride through beautiful scenery of Cape Cod.

- Ride to Cure Rare Disease is a day-long bike ride that takes riders through scenic Cape Cod at the end of summer. The ride stretches from the beginning of the newly renovated Cape Cod Rail Trail in Yarmouth, MA to Wellfleet, MA and back. Riders can choose your distance with support and refreshments along the way.
- Ride to Cure Rare Disease is accessible to all levels of riders. Regular and electric bikes will be available for rent. “E-bikes” are motorized bikes that have a maximum assisted speed of 20 mph.
- To top off a day of riding, there will be a party with food, live music and a celebration to recognize our riders, our sponsors and the quest to cure rare disease. This year, we will hold our reception at Sea Dog Brew Pub in South Yarmouth at 23 Whites Path.

UNIQUE WAYS TO GET INVOLVED- Register for the ride, start a team and fundraise. Don't want to ride? Buy a ticket to the reception, donate or become a sponsor, contribute an in-kind donation or volunteer the day of the ride.

More information on the ride can be found following this link: <http://ride.curerareisease.org>

Tickets to the reception only can be purchased at: <https://www.eventbrite.com/e/ride-to-cure-rare-disease-reception-tickets-61446898327>

CRD Third Annual Gala - Wyndham Beacon Hill Thursday, October 24, 2019

The 3rd annual Cure Rare Disease gala, will be held at the Wyndham Hotel in Beacon Hill, 5 Blossom St, Boston, MA 02114 on October 24, 2019. The event is 6:00-9:00pm (**VIP at 5:30pm with our guest being famous Red Sox pitcher Luis Tiant!**). Cure Rare Disease gala is a unique fundraising event and reception about a community united to end disease. The event honors local families who are battling diseases like muscular dystrophy. Over 200 guests are expected to attend the reception this year, helping raise funds through event fundraising, silent auctions, sponsorships and advertisements.

For more information about this event please contact me directly (rich@cureRD.org) or visit: <https://www.eventbrite.com/e/cure-rare-disease-annual-fall-gala-tickets-62826385410>

CRD \$1 Ask Campaign

In partnership with Global Partners, we recently launched a \$1 Ask campaign across 300 convenience stores in the Northeast including Xtramart Convenience Stores, Honey Farms and Alltown Convenience Stores. Look for one near you and donate a \$1 when on your next visit. Thank you to our great partners at Global who helped make this happen!

Cure Rare Disease – Precision Medicine Program welcomes new collaborators!

As CRD and our collaborators push forward in developing our individualized therapeutics program, we recently welcomed two critical collaborators – Charles River Labs and Nationwide Children’s Hospital.

We also welcomed Nationwide Children’s Hospital (NCH) Vector Core to our collaboration recently. As some may be familiar, NCH is a world-leader in AAV (adeno-associated virus) production. AAV is used to deliver therapeutics to, in our case, muscle. You can learn more about the use of AAV [here](#).



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