



# Fighting H.A.R.D. Foundation

Helping kids who Have A Rare Disease or chronic illness



## To Whom It May Concern,

Hello there! My name is Jonna Crocker, and I am the co-founder of Fighting H.A.R.D. Foundation with my sister, Alexandra Crocker. Our mission at Fighting H.A.R.D. is to help kids with rare diseases and chronic illnesses to not feel alone in their battles. We accomplish this by sending care packages, providing emotional support through social media and get-togethers, and financially assisting kids and their families by providing things like meals, groceries, and medical equipment not covered by insurance. We are currently assisting 45+ families right here in New Jersey.

With 1 in 10 Americans having a rare disease, the likelihood is that at least one of your students is dealing with a rare condition. There are many kids right here in our own community who battle with autoimmune conditions, gastrointestinal diseases, heart conditions, visual impairments, seizure disorders, chronic pain conditions, and much more. Some of these diseases are visible due to devices like wheelchairs or feeding tubes, while others are invisible to the regular person. This is why we hope to spread awareness through our Rare Disease Day campaign and provide support to these kids.

One of our largest events of the year is Rare Disease Day. Celebrated on the last day of February each year, we strive to raise awareness for rare diseases and the impact they have on many kids!

In this packet, you will find a few different ways that your school or organization can get involved! Our biggest two initiatives are Rare Your Jeans Day and our Run HARD for Rare Kids. Please take a look at all of the opportunities to raise awareness and funds! If you have any questions, do not hesitate to reach out. We would love for you to get involved in the great things happening this year.

Sincerely,

**Jonna Crocker**  
**Founder, Fighting H.A.R.D. Foundation**  
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# TABLE OF CONTENTS







- 2 RUN HARD FOR RARE KIDS
- 3 RARE YOUR JEANS DAY
- 4 WORKSHEETS/PRINT-OUTS
- 7 FLYERS
- 9 CHECK OUT PREVIOUS EVENTS!

# Run H.A.R.D. for Rare Kids 2023



Our Run HARD for Rare Kids started in 2021 as a way to safely raise funds and awareness during the COVID-19 Pandemic. The virtual run is held the week leading up to Rare Disease Day, this year being 2/21/23-2/28/23!

Ways to get involved:

-  Register your class/organization/school as a team, and have your students and staff join your team for the run!
  - Bonus - create a fundraiser for your organization and get individuals to donate!
-  Sign up to run 2, 8, or 28 miles, a 5k, or Relax for Rare with us!
-  Use hashtags #RunHARDforRareKids2023 and #RunHARD2023 on social media!
  - Share pictures of your students and staff getting involved
-  Set up a physical run at your school or another location and invite your network
-  Win prizes by gaining more participants and raising money
-  Teams with the most participants and most successful fundraisers will win prizes!




Sign up now at <https://runsignup.com/Race/NJ/Anytown/RunHARDForRareKids2023>  
or by scanning the QR code located below!










# Rare Your Jeans Day 2023



Why rare your jeans?

-  80% of rare diseases are caused by rare or faulty genes
-  Denim patterns are used in rare disease campaigns globally
-  Helps to raise awareness in a fun, creative, and educational way!

Ways to get involved:

-  Have your students decorate their jeans and wear them on 2/28/23 (or any designated day that works for your school/organization)
  - Raise awareness for a specific illness or person, or just make them rare!
-  Have staff members wear jeans and donate on rare disease day
-  Have students color the paper jeans and put them on their lockers!
  - See worksheet on page 4 to print out and distribute!
-  Make copies of the HARD Facts sheet and spread them across the school
  - See Fighting H.A.R.D. Rare Facts on page 8
-  Wear your Fighting H.A.R.D. T-shirts or awareness t-shirts on a designated day!
-  Donate \$1 or any amount to our organization. All money raised goes directly to kids battling rare diseases in our local community
-  Talk to your school's student council, art classes, key club, etc to make the day an even greater success! Feel free to implement any other ideas that you have as well!





# Fighting H.A.R.D. Foundation

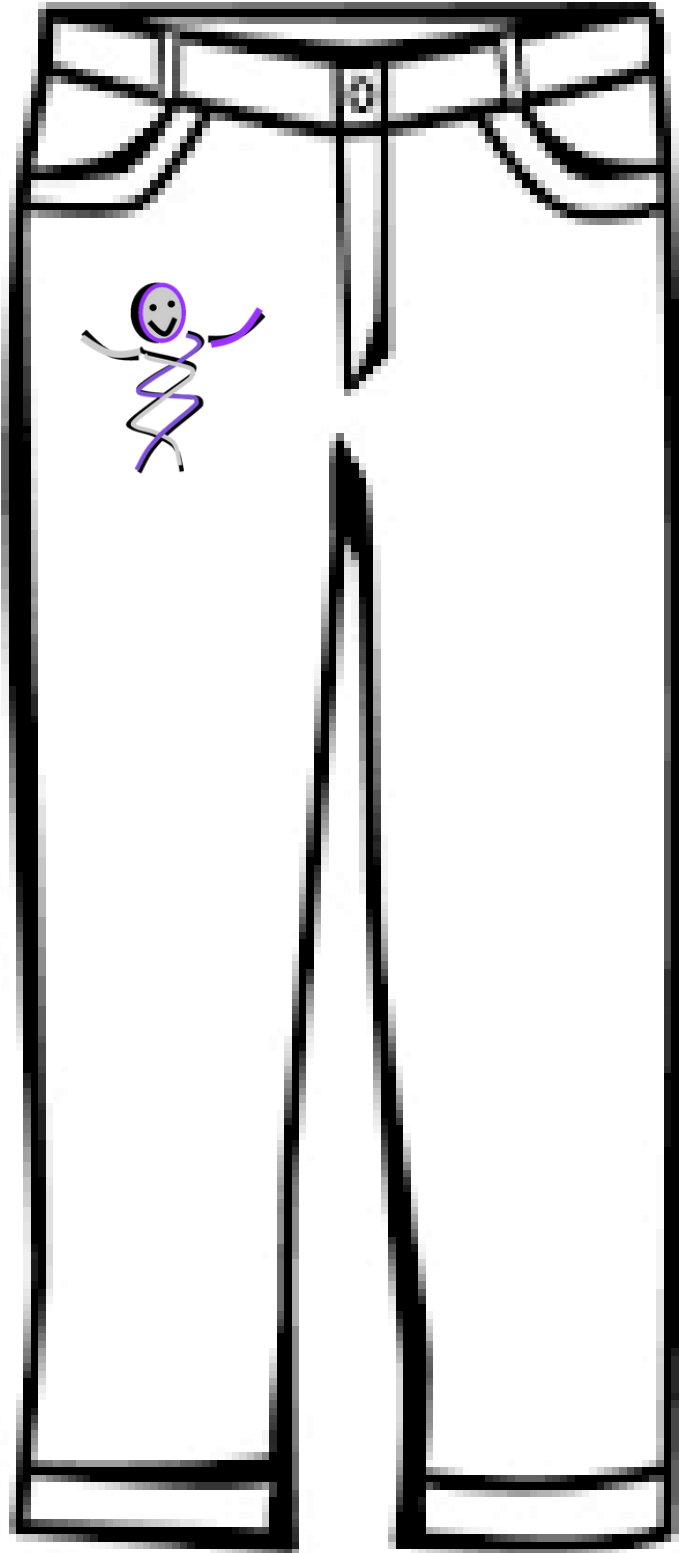
Helping kids who Have A Rare Disease or chronic illness

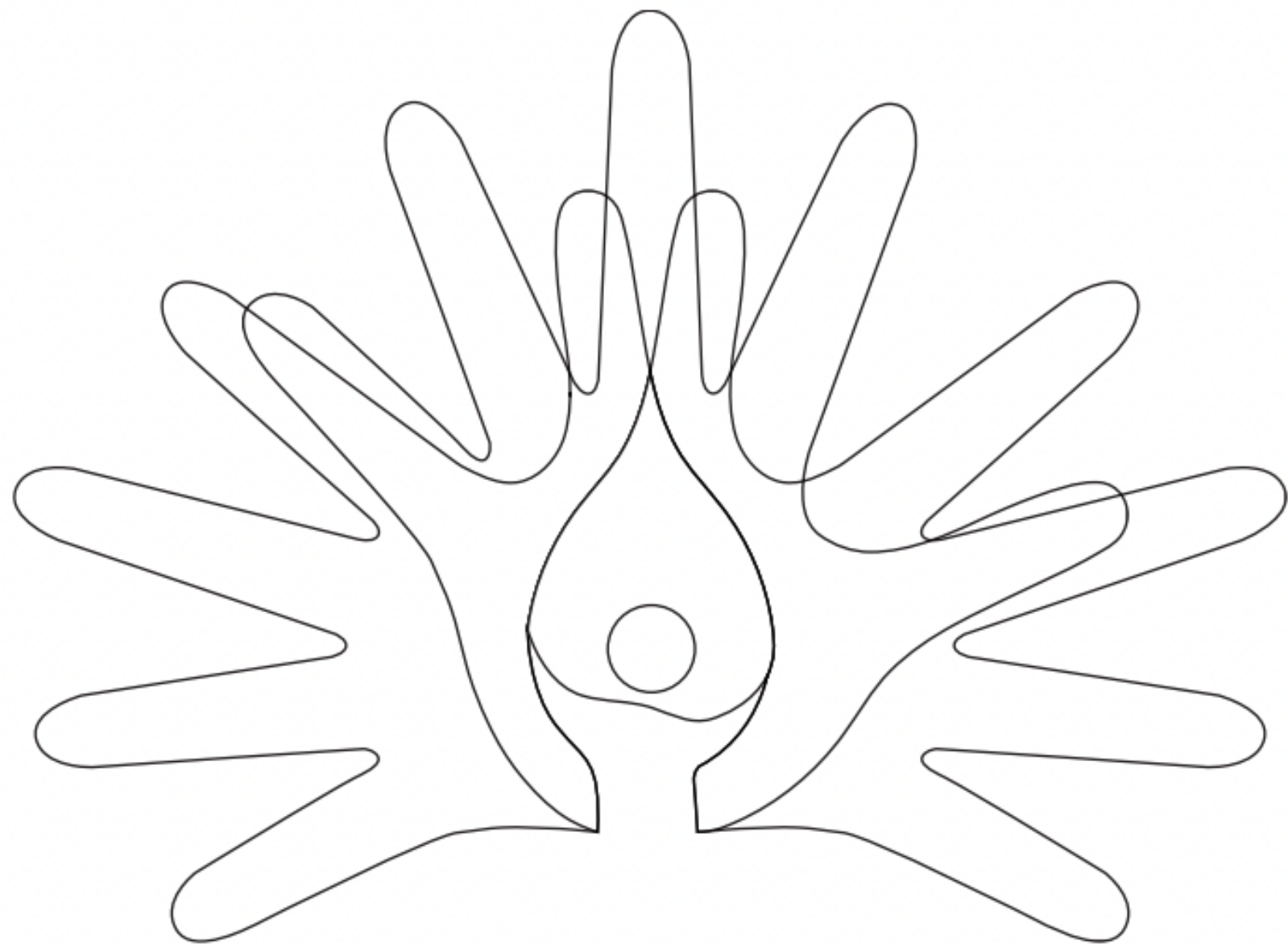
## Rare Your Jeans Day!

Decorate this pair of jeans to help raise awareness for kids with rare genes!

Hang them on your locker so everyone can see!

Thank you for Fighting H.A.R.D. with us and joining in on our rare disease day celebration!





# RARE DISEASE DAY®

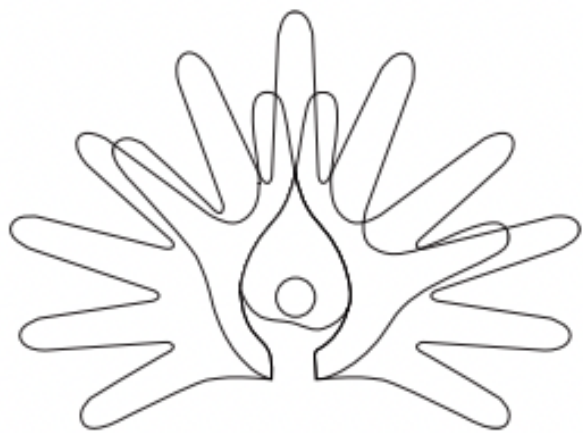


**NORD®**  
National Organization  
for Rare Disorders

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NORD: Fighting for the rare community every day for nearly 40 years. NORD is committed to the identification, treatment and care of rare disorders through programs of education, advocacy, research and patient support services. NORD does not recommend or endorse any particular medical treatment but encourages patients to seek the advice of their clinicians.  
NORD is a registered 501(c)(3) charity organization. NRD-2192



SHOW  
YOUR  
STRIPES®  
ON RARE DISEASE DAY®



RARE DISEASE DAY®





# Fighting H.A.R.D. Foundation

Helping kids who Have A Rare Disease or chronic illness

Celebrate Rare Disease Day and join in on our 3rd annual



**VIRTUAL RUN!**

Join from  
anywhere!

Earn badges  
for  
fundraising  
milestones!

## February 21 - February 28

Run, Walk,  
or Relax for  
Rare!

Raising awareness and funds  
for kids with rare diseases!

Join or  
create a  
team!



#RunHARDforRareKids  
#RunHARD2023

[www.fightinghardfoundation.org](http://www.fightinghardfoundation.org)

Tax ID: 474652204







# FIGHTING H.A.R.D. RARE FACTS!



## THE HARD FACTS:

-There are over 7,000 known rare diseases in the United States

-it takes an average of 8 years and 10 specialists to receive an accurate diagnosis of a rare disease

**A RARE  
DISEASE IS  
ANY DISEASE,  
DISORDER,  
ILLNESS, OR  
CONDITION  
AFFECTING  
FEWER THAN  
200,000  
PEOPLE**

**80% OF RARE  
DISEASES  
ARE GENETIC  
IN ORIGIN!**

## KIDS FIGHTING H.A.R.D.

-30 million people in the U.S. have been diagnosed with a rare disease - over half of them are children

-Of the rare diseases identified, over 3,500 of them affect children

-55% of rare disease families will incur direct medical expenses not covered by insurance



For more information About Fighting H.A.R.D., or to donate directly through our website, please visit [www.fightinghardfoundation.org](http://www.fightinghardfoundation.org)  
Federal Tax ID 47-4652204 Thank you for your support!

# Check Out Previous Events!

