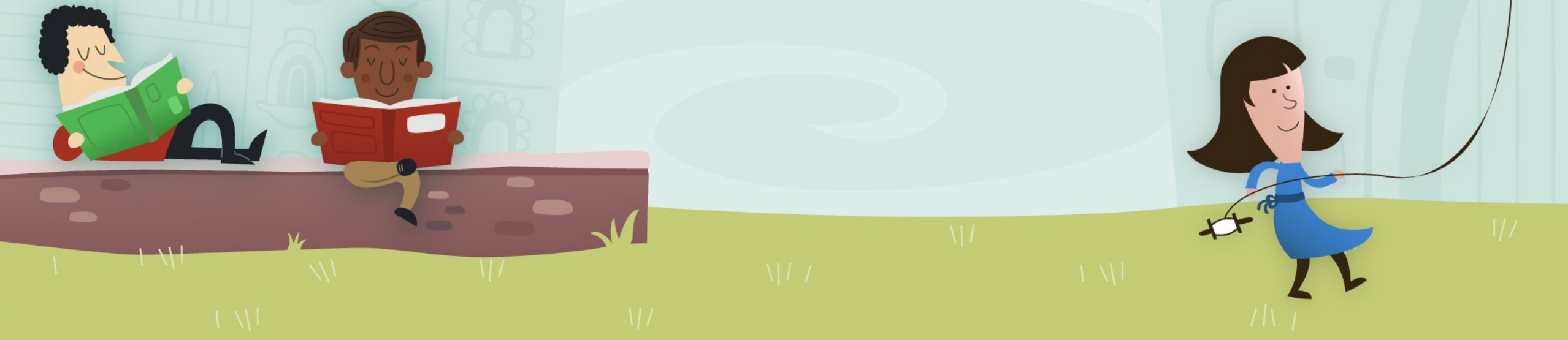


The Gift of Time: Management of Duchenne's Muscular Dystrophy in the MIH Environment

R. Farnsworth B.S., CP-C, CCP-C
Clinical/Operational Coordinator
Delta County Ambulance District



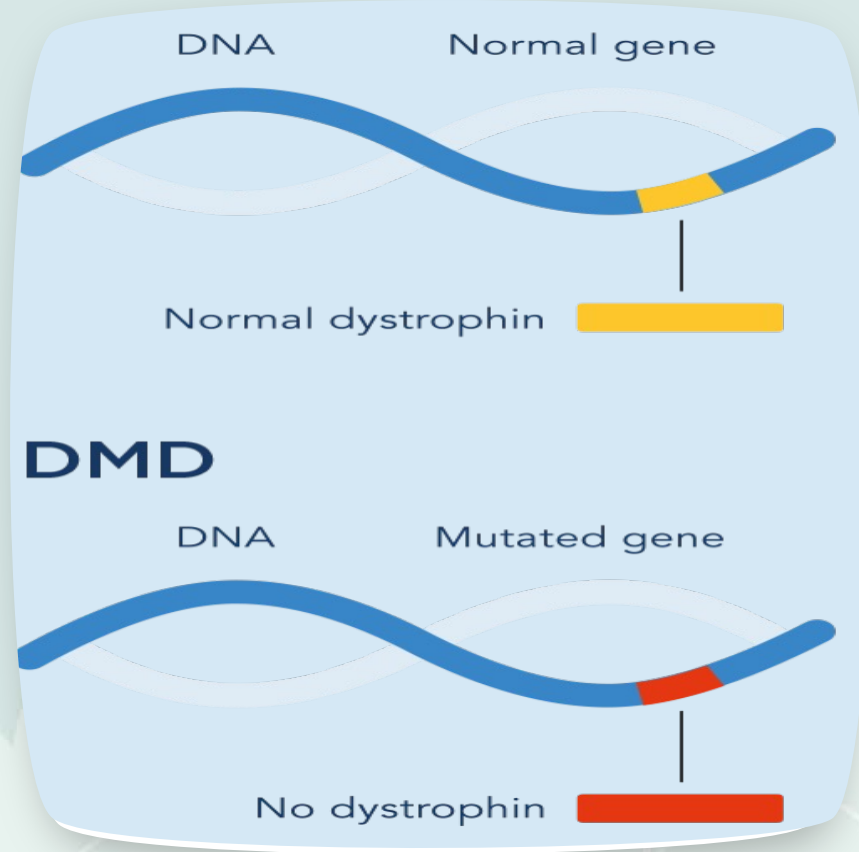
Time is more
valuable than
money. You can
get more
money, but you
cannot get
more time.

-Jim Rohn





Duchenne's Gait



Duchenne's Genetic Mutation



Epidemiology

- 1:3500 – 1:5000 incidence per male births
- X- linked recessive condition
- Maternal transmission in roughly 2/3 of cases
- Presentation usually occurs by 5 y/o with motor delays
- Wheelchair bound on average by 13 y/o
- Mean life expectancy is 29 y/o
- 80% of cases result from exonic deletion affecting the dystrophin gene



The Case:

- 11 y/o male
- Had been enrolled in an experimental drug trial requiring weekly travel to Portland, OR and Salt Lake City, UT
- Family was separated during these treatments.
- The patient lives in a remote region of Colorado
- Contacted by the specialty pharmacy, looking for someone to provide in-home infusions.

The Team

Children's Hospital

Orsini Pharmacy

Sarepta Pharmaceuticals

Delta County Ambulance

District MIH Team



Treatment

- Port Access
- Infusions
- \$20k per infusion
- Exon skipping medication, allowed for the genetic coding of a shortened version of dystrophin.



Changing the World

**BE THE CHANGE
THAT YOU WISH
TO SEE IN
THE WORLD**

(MARTIN LUTHER KING JR.)

HDQUOTES.COM



Lessons Learned

Diverse Partners Can Make a Difference

- Medicine is not always about the cure. The clinical part is easy.
- Mobile Integrated Healthcare can change the way populations access medical care.
- A small team, with a common goal, can change the world for a single patient and a single family.
- Change starts with an N of 1.



References

Kariyawasam, D., D'Silva, A., Mowat, D. *et al.* Incidence of Duchenne muscular dystrophy in the modern era; an Australian study. *Eur J Hum Genet* (2022). <https://doi.org/10.1038/s41431-022-01138-2>





ANY
QUESTIONS
?

R.Farnsworth B.S., CCP-C, CP-C
Clinical/Operational Coordinator
Delta County Ambulance District
rfarnsworth@dcadems.com
(970)-424-3993

