Life’s Lemons

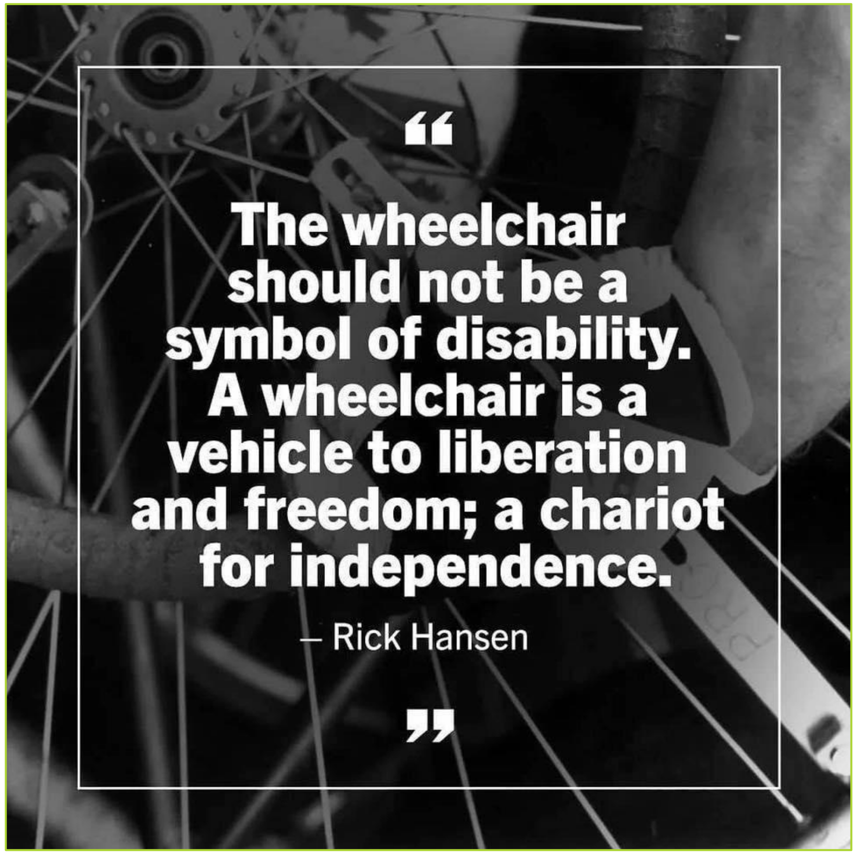
Kendra Gottsleben

Younger Years

- Age 4 with MPS VI (Mucopolysaccharidosis Type VI)
- Parents taught me to never let myself give into the world and to look at life with a positive outlook.
- Family always recognized and focused on my abilities and rarely focused on what I couldn't do.

Educators Recognized & Focused on Abilities

- Was mainstreamed throughout school in Vermillion, SD.
- Throughout my life— for the most part educators recognized and focused on what I could do.
- They saw my abilities and rarely focused on what I couldn't do.
- But there were a few occasions where I did experience my disability being seen 1st and my ability 2nd.



> “The wheelchair should not be a symbol of disability. A wheelchair is a vehicle to liberation and freedom; a chariot for independence.
>
> – Rick Hansen”

High School

- Junior year I set a goal to take American Heritage (an AP class) and Algebra II.
- Met with an advisor who told me, "Only students who planned on attended college would take those classes."
- She was seeing my disability 1st.
- I took those classes and ended my high school career part of the 2004 graduating class with a 3.6 GPA and as a member of the National Honor Society.

College

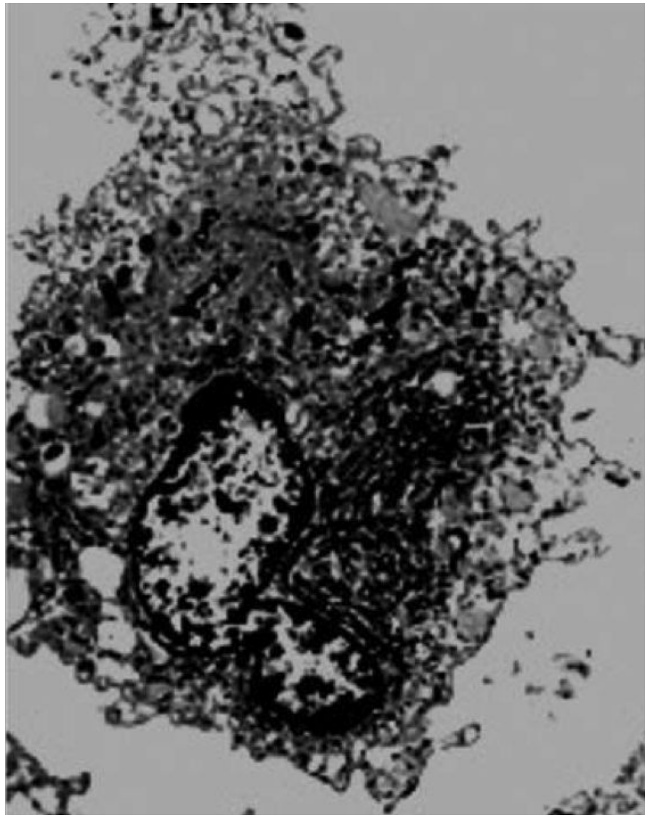
- Had a professor assume other students were telling the truth and I was not.
- Was told I was not cut out for graduate school.
- Was accused of cheating on a test.
- Began to wonder, "Did my size and wheelchair create doubt in my ability?"
- 2010 Augustana University graduate with a double major in Sociology and Psychology.

Genetics

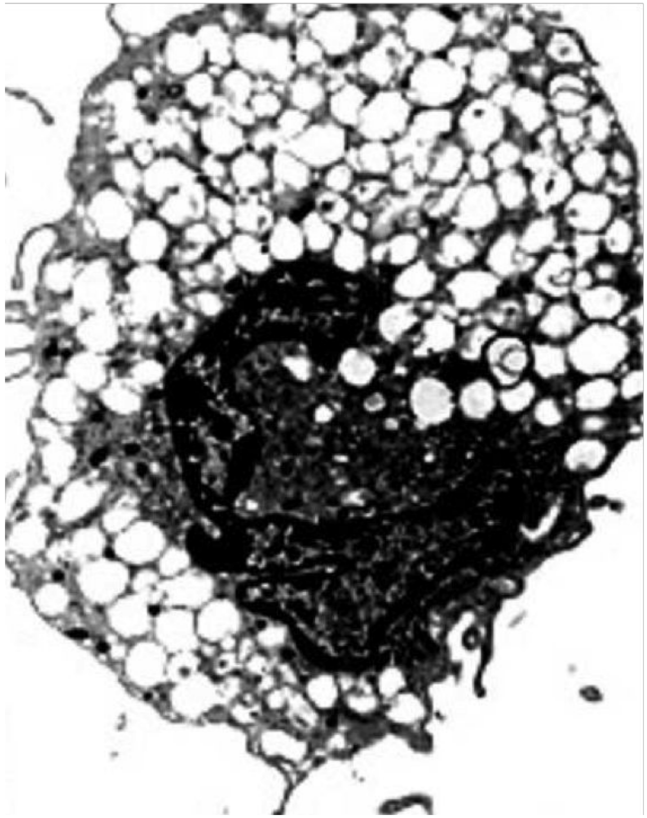
- People with MPS disorders don’t make the enzyme needed to break down the sugar chains.
- Over time, waste needs to be recycled within the cell, it doesn’t get broken down, and the build up affects connective tissue, heart, lungs, eyes and other vital organs.
- All the MPS disorders have cells that don’t recycle the unwanted material into something that the cell can use.

Lysosomal Storage Disease

Normal Cell



Lysosomal Storage Disease Cell



1. Neufeld EF, Muenzer J. In: *The Metabolic and Molecular Bases of Inherited Disease*. 2001:3421–3452.

Photos courtesy of BioMarin Pharmaceutical Inc.

Treatment

- Participant of a clinical research enzyme trial in Oakland, Cal. in 2002.
- The clinical research trial was a study on the missing enzyme that my body doesn’t produce.
- The goal was to receive FDA approval for the drug treatment called, NAGLAZYME. Once approved other children and adults with MPS Type VI were able to receive the treatment.
- In 2005 the FDA approval was granted.
- I have been receiving weekly infusions since 2002 and will have to continue this for the rest of my life.

We are the one's who determine the attitude and the approach we take in life! I take the positive one!

Obstacles of Life

- I have had my fair share of obstacles due to MPS, but I have learned to overcome them.
- The obstacles have made me a better person and have taught me that I determine my own success.
- We all have obstacles to overcome in our lives.
- Life will never be easy for any of us…it is just the way it is for us all.

So with that in mind…

Do the things you are most passionate about in life!

Life’s Passions

ADVOCATE

- National MPS Society Adult Resource Committee Member
- South Dakota “Ability for Hire” Campaign
- Naglazyme Documentary
- Self-Advocate Mentor

AUTHOR

- ***Live Laugh Lemonade: A Journey of Choosing to Beat the Odds***
- ***Kendra's Lemonade***
- ***Kendra's Perfect Dance Routine***
- Writing is a way to share my story, and to help others with the idea of acceptance that builds positivity within our world.

ADAPTIVE CLOTHING

- 2016 Runway of Dreams Foundation runway model.
- Dressing for Success in Life.
- Pursuing a dream even if it doesn't develop the way I had planned.

MARKETING COMMUNICATION SPECIALIST

- 15 years at the Center for Disabilities.
- Blends two worlds I grew-up in; education and medicine.
- Talk with medical students about disability etiquette and healthcare transitions.

FOUNDER & EXECUTIVE DIRECTOR

Rare by Design

- Mission: Celebrating the rare that makes us unique and extraordinary.

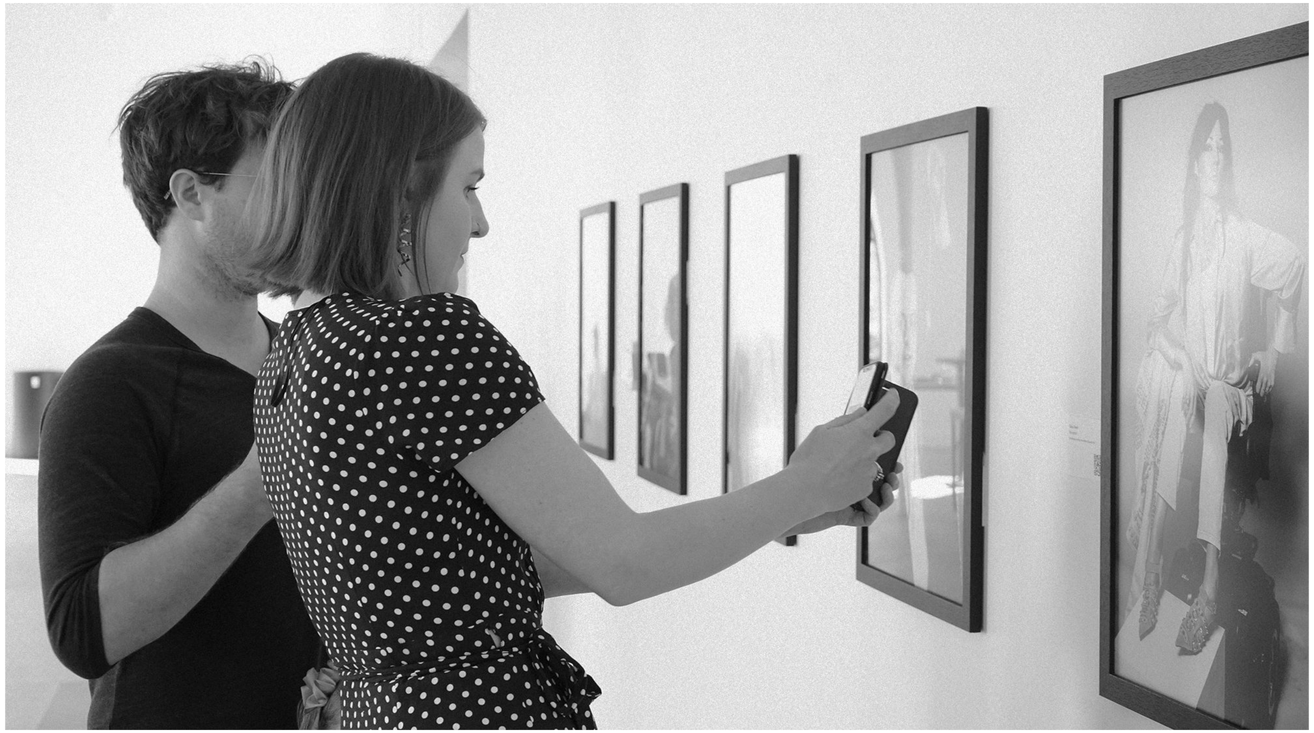
- We work towards creating awareness, inclusion and representation for individuals with a rare disease and disability.

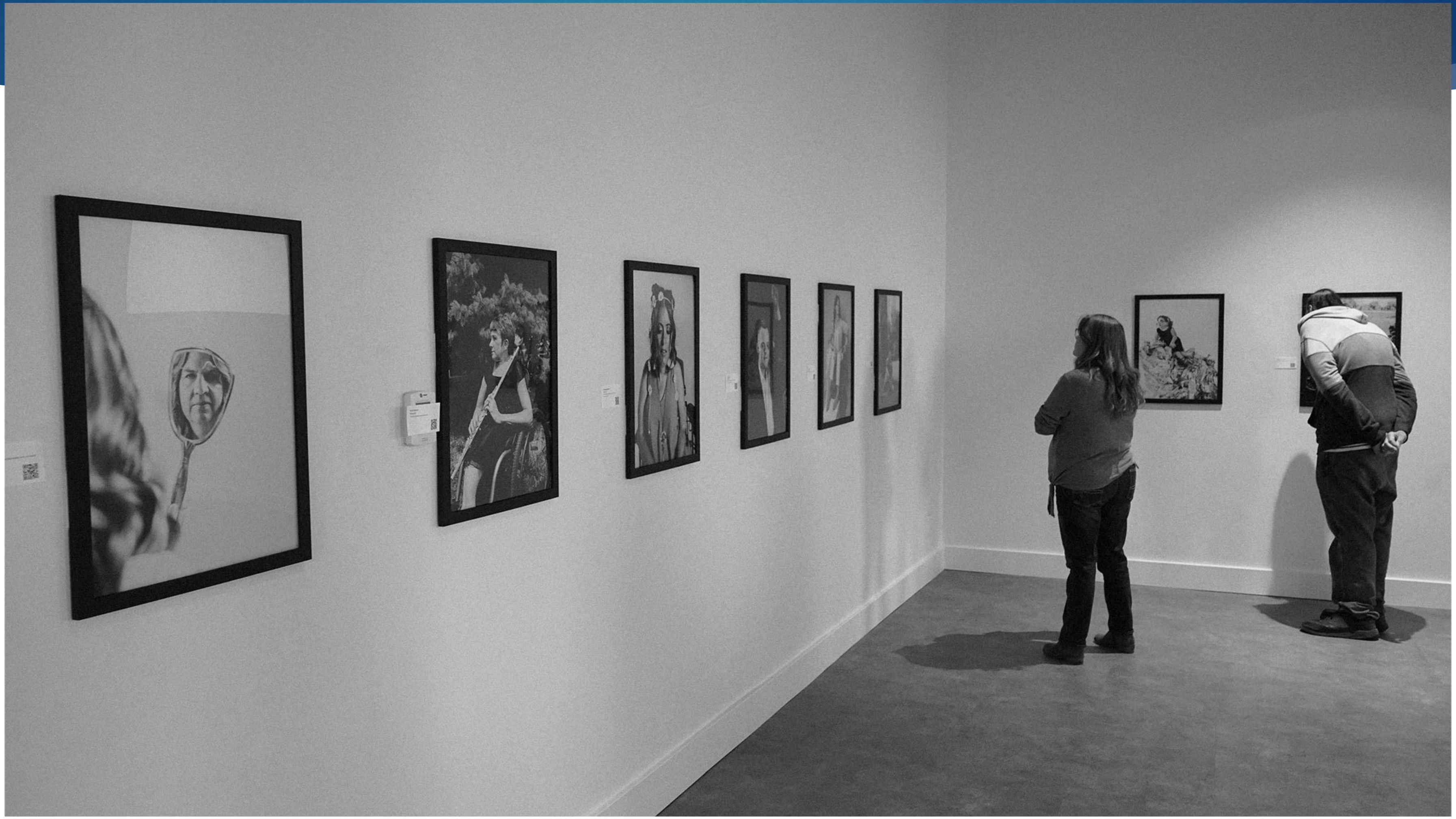
- www.rarebydesign.org

THE Style SHOW

A RUNWAY TO EMPOWER

Refocus Exhibit





Representation Matters

PUBLIC SPEAKER

- **TEDx** Sioux Falls & **TEDx** USD
- 10th & 16th Annual Lysosomal Disease Network WORLD Symposium
- Kids from 3rd grade to 12th
- Community organizations

Advice from Kendra

- See people for people first, even if someone has a disability or not.
- We all have different abilities no matter what we look like or have to deal with in life.
- Having a disability doesn't mean goals aren't achievable. At times they have to be tweaked to be achieved, but are possible.
- Remember to take time to ask questions and listen to responses.
- Own who you are and be proud of it. Knowing yourself is the first step to acceptances and the key to success.

Quote I Live By…

I look at obstacles in life as "lemons" and turn them into "lemonade."

"When Life Hands You Lemons…Make the ***Best*** Lemonade Possible"

Thank You!

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