The background of the slide is a green chalkboard. In the lower-left quadrant, two pieces of pink chalk are positioned diagonally. The chalkboard is covered with faint, white chalk drawings, including a large heart shape in the center, a smaller heart to the left, and a vertical line with a small hook at the bottom. The overall lighting is soft, creating a gentle glow across the scene.

# **Chronic Illness and School Reintegration: How We Can Help**

**Karen Norman, RNC  
Melissa Schmautz, MS, CCLS**

# Objectives

- Define chronic illness
- Increase awareness on the lack of preparation and training for school personnel when working with students and families with chronic illnesses
- Identify components of a successful school reintegration program and ways to recognize and utilize additional resources
- Introduce ways to maintain a presence with the school after a school reintegration

**Do you work with or live with a child who has a chronic illness?**



# What is Chronic Illness?

- Health problem that lasts over 3 months
- Affects child's normal activities, may require multiple hospitalizations, possible home health care involvement
- Estimated that 15-18% of children in the US live with a chronic health condition



# Types of Chronic Health Conditions

- Asthma
- Diabetes
- Cerebral Palsy
- Sickle Cell Anemia
- Cystic Fibrosis
- Cancer
- Seizures
- Spinal Bifida
- Heart Problems
- ETC.

# Austin's Story (Video)



# Side Effects for Pediatric Patients

- Unusual or easy irritability
- Change in ability to pay attention
- Change in sleep habits
- Sad or depressed mood
- Loss of interest in favorite toys or activities



# Cognitive Effects

- Memory during lectures/assignments
- Learning ability regarding material
- Reasoning with peers and teachers
- Speed of mental processing
- Attention or concentration
- Difficulty understanding speech or writing
- Difficulty speaking or writing
- Inability to organize thoughts and ideas
- Trouble following conversations





# Social Problems

- Trouble with turn taking or topic selection
- Problems with changes in tone, pitch or emphasis to express emotions, attitudes or subtle differences in meaning
- Difficulty deciphering nonverbal signals
- Trouble reading cues from listeners
- Trouble starting or stopping conversations
- Inability to use the muscles needed to form words (dysarthria)



# Behavioral Problems

- Difficulty with self-control
- Lack of awareness of abilities
- Risky behavior
- Inaccurate self-image
- Difficulty in social situations
- Verbal or physical outbursts



# Emotional Problems

- Depression
- Anxiety
- Mood swings
- Irritability
- Lack of empathy for others
- Anger
- Insomnia
- Changes in self-esteem



# Effects on Development

- Executive Functioning

- *Problem-solving*
- *Multitasking*
- *Organization*
- *Decision-making*
- *Beginning or completing tasks*

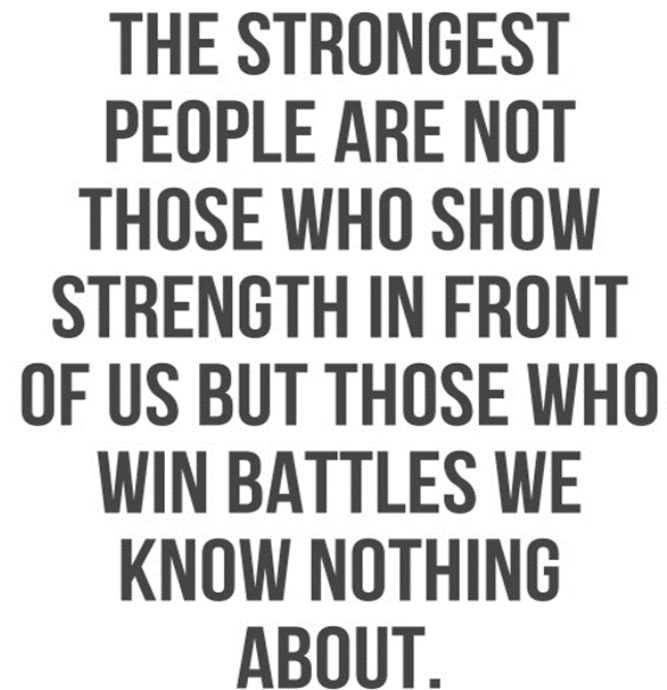
- Sensory Problems

- *Persistent ringing in the ears*
- *Difficulty recognizing objects*
- *Impaired hand-eye coordination*
- *Blind spots or double vision*
- *A bitter taste, a bad smell or difficulty smelling*
- *Skin tingling, pain or itching*
- *Trouble with balance or dizziness*




SMILE  
IT'S EASIER THAN  
EXPLAINING WHY YOU'RE SAD

I keep it all to myself.



**THE STRONGEST  
PEOPLE ARE NOT  
THOSE WHO SHOW  
STRENGTH IN FRONT  
OF US BUT THOSE WHO  
WIN BATTLES WE  
KNOW NOTHING  
ABOUT.**



You never  
know how strong  
you are until being  
strong is the only  
choice you have.

-Bob Marley



# Are You Stressed??



# Background

- Gap in services between hospital and school
- Lack of funding for local school reentry program
- Wanted to identify:
  - Where were school counselors at with their understanding of chronic illness?
  - What did they need to know?

# Literature Review

- Effects on School Counselors
  - Frequency of students reentering school following hospitalization from chronic illnesses continues to increase (Martinez & Ercikan, 2009).
  - Knowledge and training when working with students with disabilities is lacking (Milsom & Akos, 2003).





# Research Questions

- 1) To what extent are school counselors prepared to work with children with chronic illnesses reentering school following hospitalization?
- 2) What are the educational/training needs of school counselors when working with students with chronic illnesses returning to school following hospitalization?
  - Surveyed all currently practicing and credentialed ND school counselors who had access to the NDSCA listserv

# Results

- Preparation

- Strategies to facilitate coping: 77% “NO”

- Adequately prepared them to work with students diagnosed with chronic illnesses: only 2% (n = 1) strongly agreed
    - Adequately prepared them to work with students reentering school after extended hospital stays: 19% (n = 12) strongly disagreed, 32% (n = 20) somewhat disagreed
    - Provided adequate information on ways to help a student understand his/her chronic illness: only 2% (n = 1) strongly agreed

# Results continued

- School Environment
  - Made aware of side effects and treatment: 56% somewhat agreed
  - Familiarity with resources: only 53% somewhat familiar
  - Awareness of trainings on therapeutic interventions: 38% slightly aware, 30% not at all aware
- School Reintegration
  - Services to prepare a classroom: only 10% were extremely aware of services
  - Adequate training to educate student's classmates: 22% somewhat disagreed, 10% strongly disagreed

# Results continued

- School Reintegration
  - Aware of available services to prepare school population: 56% “NO”
  - Suggestions participants made:
    - Collaboration between school and medical personnel
    - Trainings and breakout sessions at conferences
    - Access to websites regarding strategies and tips
  - 44% indicated “YES”
  - Services they found helpful:
    - Making referrals
    - Utilizing outside agencies
    - Contacting local hospitals
    - Increasing communication between parent, student, school and medical community



# Results continued

- School Reintegration
  - Information on side-effects: 81% “YES”
  - Made aware of trainings on:
    - Chronic illness: 76% “NO”
    - Students returning to school following hospitalization: 85% “NO”
  - Taken trainings on:
    - Self-worth: 29%
    - Behavior: 29%
    - Physical Appearance: 16%
    - 67% had taken no trainings in these three areas

# Significance

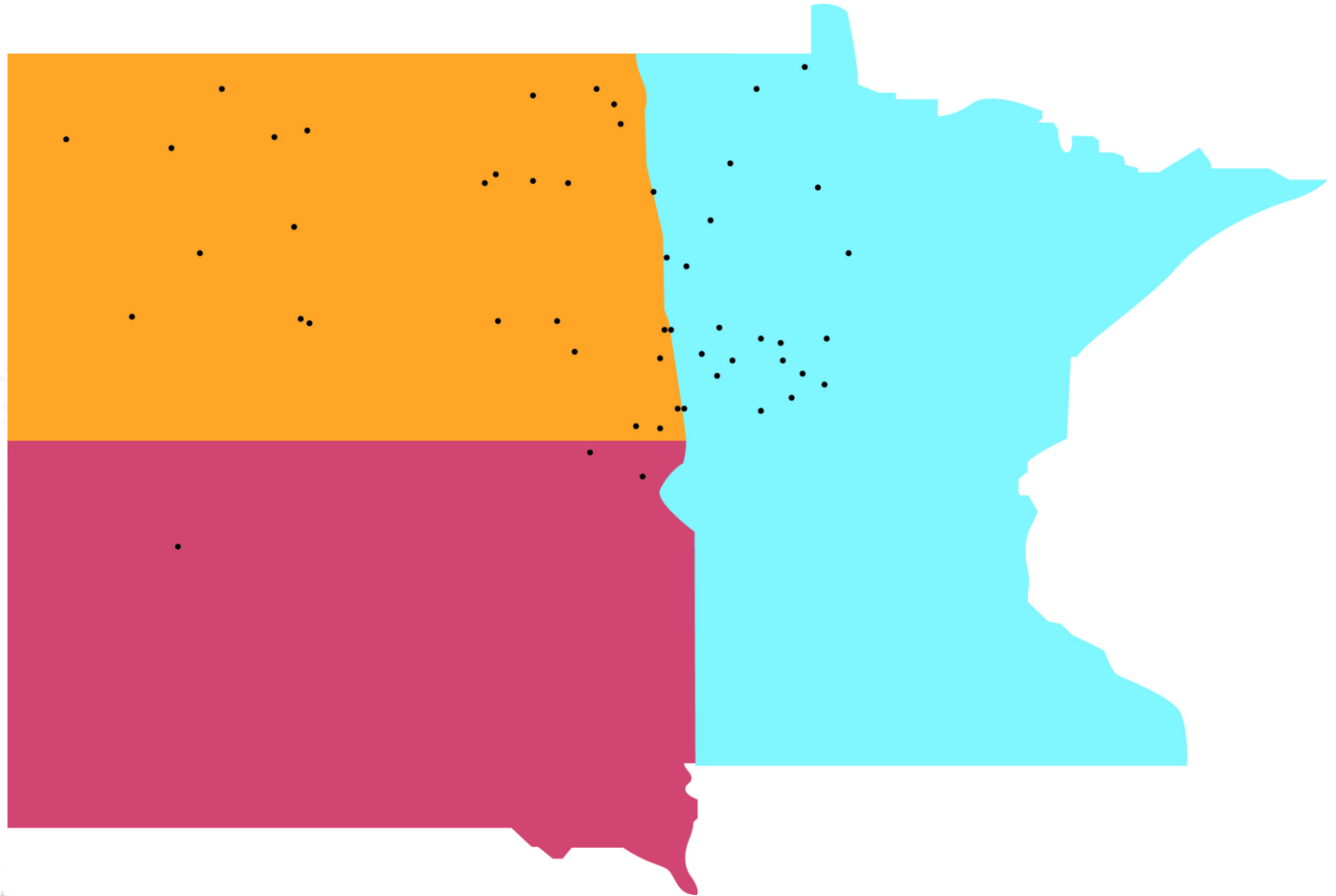
- Research (ND school counselors):
  - 86% have worked with 1 or more children identified as reentry students
  - 77% stated “no” when asked if graduate programs discussed strategies to facilitate coping with this population



# Nuts and Bolts

- History of Sanford Children's School Reentry
- Components of the Program
- Population Served
- Issues with Funding

**Oh the places we've been....**





# Current Strategies

- Hospital tutor services
  - *Working with and assessing child prior to discharge*
- School Reintegration
  - *Explanation for children AND staff*
- Coordinated Treatment Centers
  - *Late Effects*
  - *Cerebral Palsy*
  - *Cystic Fibrosis*
  - *Traumatic Brain Injury*
  - *Downs Syndrome*



# School Reintegration Program

- What is it? How did it happen?
- How do we treat it?
  - *Surgery*
  - *Tests*
  - *Medicines*
  - *Therapies*
- Continued treatment?
  - *Hospital/clinic follow-up*
  - *Medicine*
  - *Therapies*

# School Reintegration Program continued

- Points we address
  - *Is the child different?*
  - *Can you catch it?*
  - *Side effects?*
  - *New, special accommodations?*
- Monkey in My Chair
  - *Program for oncology patients*



# School Reintegration Program continued

- What can friends/classmates do to help?

- *Keep them connected*

- Send cards, letters, pictures, email, text, social media, Facetime, Caringbridge



- What can friends/classmates do to help?

- *Offer to carry books*

- *Offer to help with school work*

# School Reintegration Program continued

- Meet with teachers/staff *and* parents/guardians
  - *Address concerns*
  - *Provide recommendations*
    - Need 504 plan, IEP?
- Provide contact information for future questions





# Strategies for Improvement and Collaboration

- Increased presence/collaboration with schools
- Contacting school counselors/administration
  - ROI
  - Professional Development/trainings
- Advocate for the child's needs! What needs to be adapted?
- Continued follow-up
  - **DOING MORE**

# Strategies for Coping

- Join a support group
- Journaling
- Assist parents and school with setting a structured routine
- Allow time for “brain breaks”
- Adapt work expectations or tasks to fit child’s needs
- Create a supportive learning and home environment that doesn’t overstimulate
- Provide “fidget” items as needed



# Conclusion

- Many families are affected by chronic illness
- Lack of education for school counselors/personnel on how to work with children who are affected by chronic illness
- Appears to be a strong need for experience, preparation, and implementation of programs on school reintegration







## Take Away.....

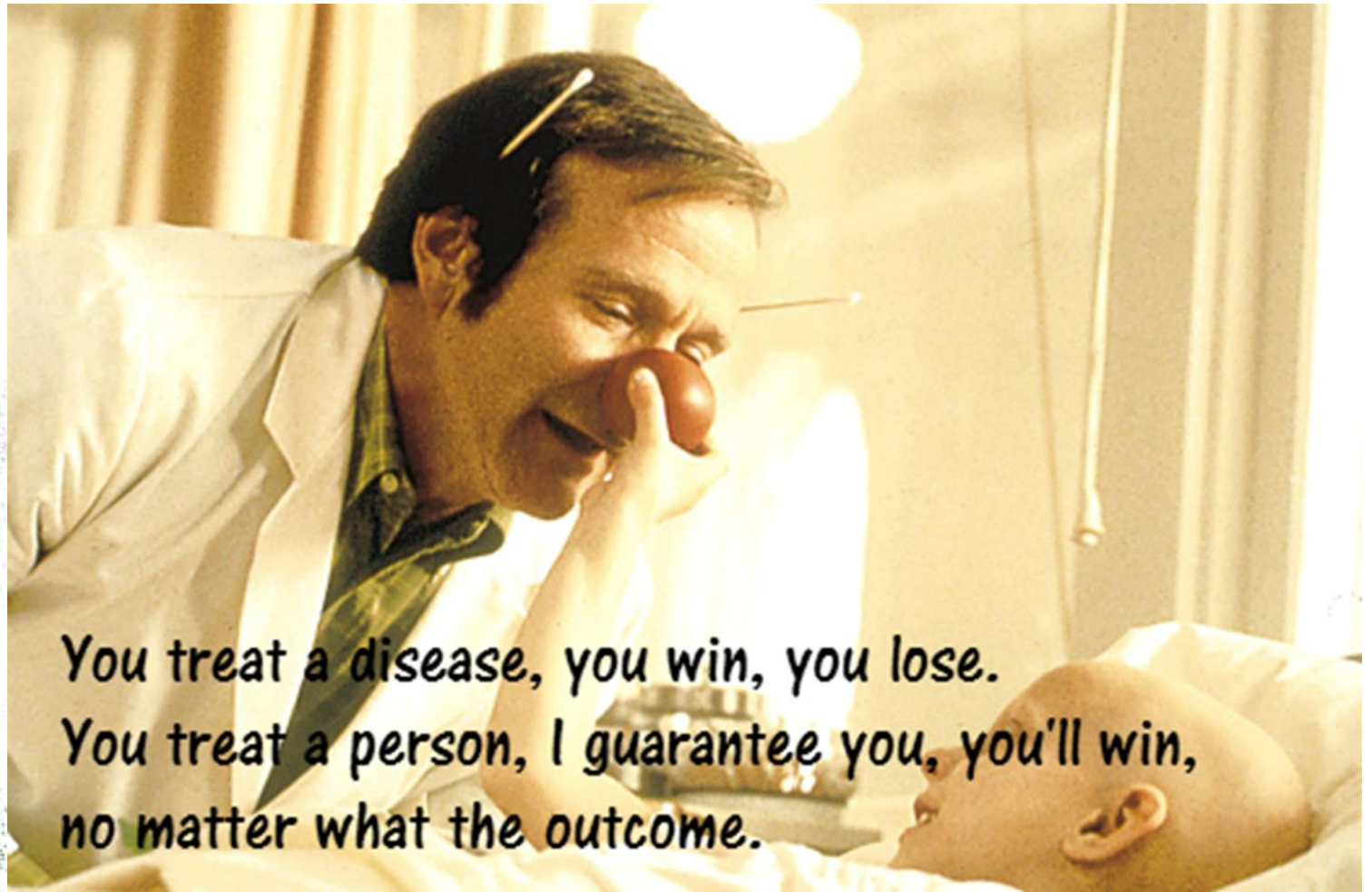
- **EVERYONE** needs to work together to help children with chronic illness succeed!!

A green chalkboard occupies the left side of the image. Two pieces of pink chalk are lying on the board, one upright and one lying on its side. A white arrow is drawn on the board, pointing upwards and to the right. The right side of the image is a plain white background.

**QUESTIONS?**

# Contact Information

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You treat a disease, you win, you lose.  
You treat a person, I guarantee you, you'll win,  
no matter what the outcome.

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