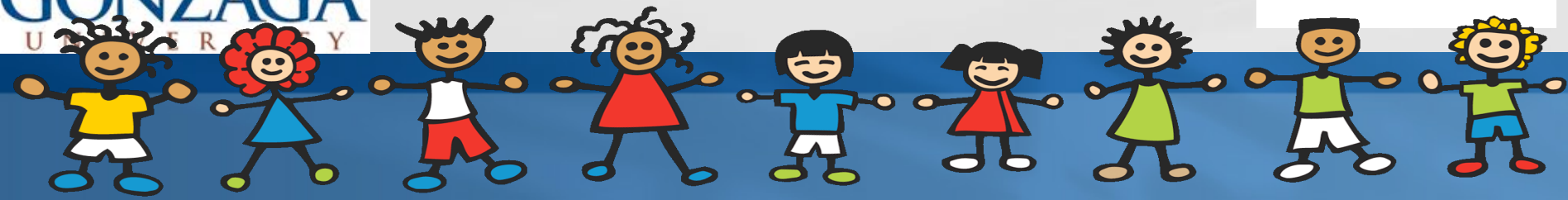


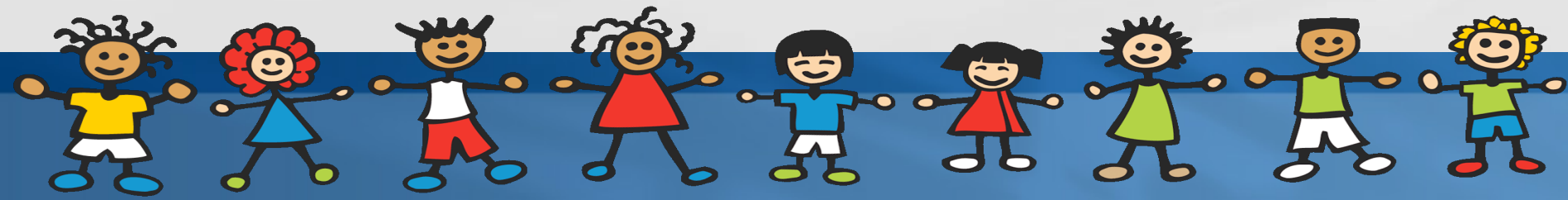
The Parent Experience of Stress and Coping When Caring for a Child With Mitochondrial Disease

By:
Brenda Senger
Spring 2013



Introduction

- RN 28 years
- Nurse Educator
- Mother of 4 children
- May 23, 2003
- 4 y/o daughter
- Probable Mitochondrial Disease



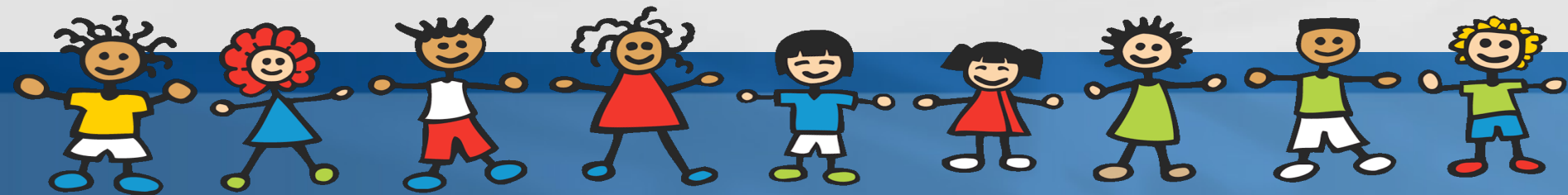
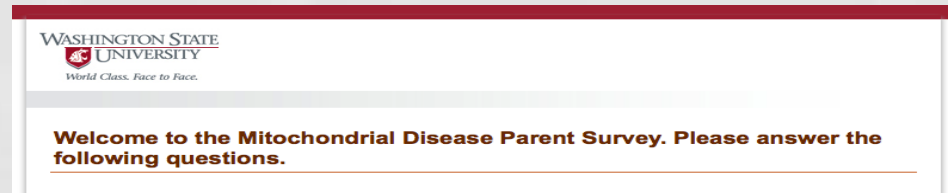
Journey to Dissertation

3

- PhD program
- Goal: identify stress and coping in parents of children with Mito
- Educate health care professionals
- Provide support to parents of children with Mito

Take this survey

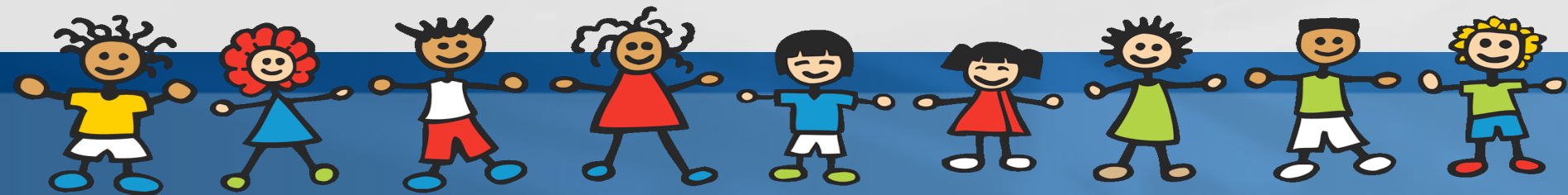
https://wsunursing.qualtrics.com/SE/?SID=SV_cOnqRUyfTTHO5a5



Objectives

4

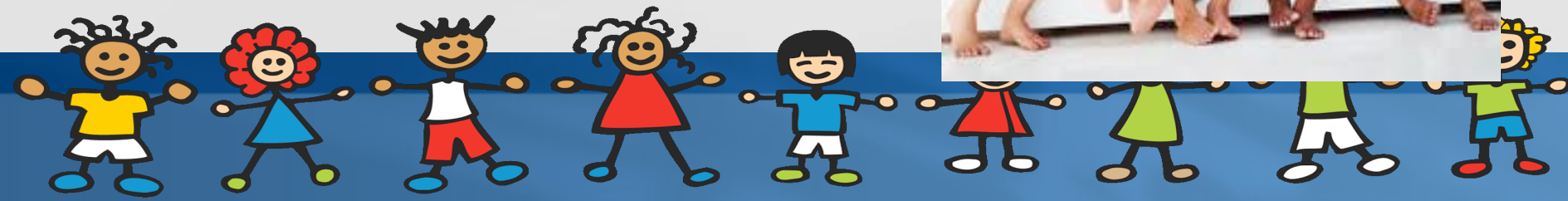
- Describe what is known about stress and coping when caring for a child with chronic illness
- Describe what is known about the needs of parents caring for a child with Mito
- Discuss the importance of identifying the specific needs of stress and coping for parents of children with Mito



Chronic Illness in Children

5

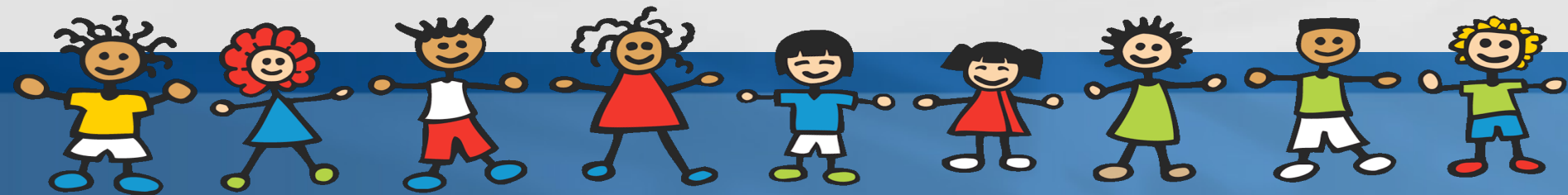
- Increased prevalence
- Larger population of children with special needs
- Medical assistance is helping these children grow into adulthood with increased functioning and better quality of life



Chronic Illness in Children

6

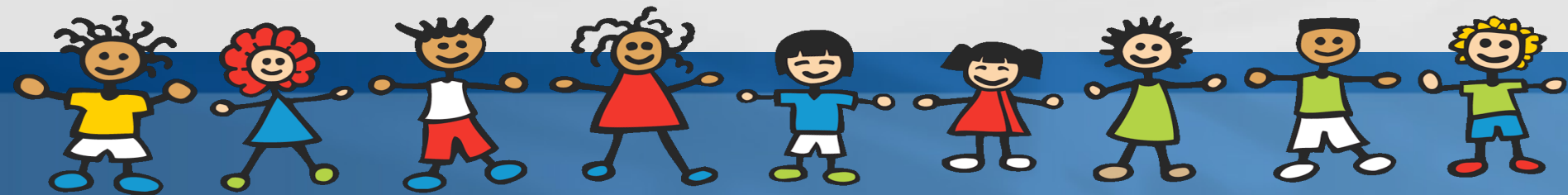
- Complex
- Unpredictable trajectory
 - Neurodegenerative disease can deteriorate either within a short period of time or over many years.
- Challenges can be overwhelming:
 - Physical, emotional, financial, social, spiritual
 - Anxiety, stress, and uncertainty



Chronic Illness in Children

7

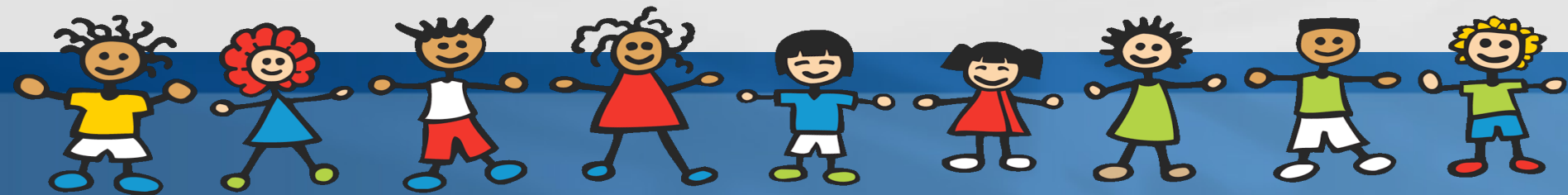
- Chronic Illness is a stressor for parents and children
- Relationship between parent stress and child distress
- The higher the parental stress the greater the level of distress in the child
- Parental maladjustment depends on length of illness, functional impairment, severity of illness



Chronic Illness in Children

8

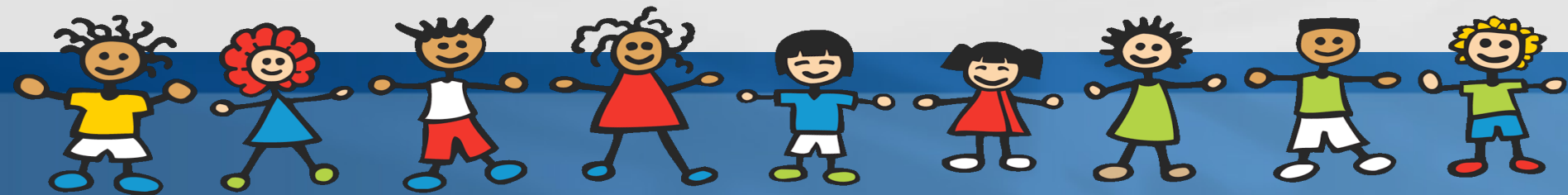
- Parents of children with multiple and severe chronic illness have more unmet needs than children with a single chronic illness
- Unmet needs are proportionate to the severity and complexity of the child's illness.
- Mito is complex affecting many body systems



Needs of Parents

9

- Medical care
- Finding a skilled provider
- Fragmentation of care
- Getting referrals
- Travel for medical appointments
- Organizing home health care
- Financial burdens
- Insurance coverage
- Activities of Daily Living
- Coordinating with schools and other organizations

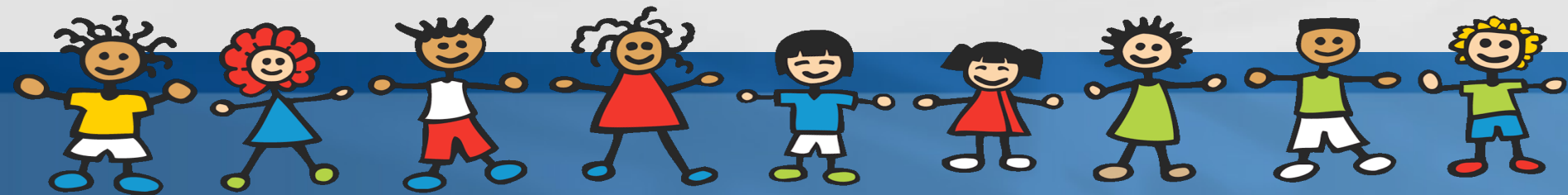


Visible Demands

- Medical care
- Treatments
- Monitoring symptoms
- Physical demands
- Activities of daily living
- Developmental delay
- Impaired social skills
- School needs

Invisible Demands

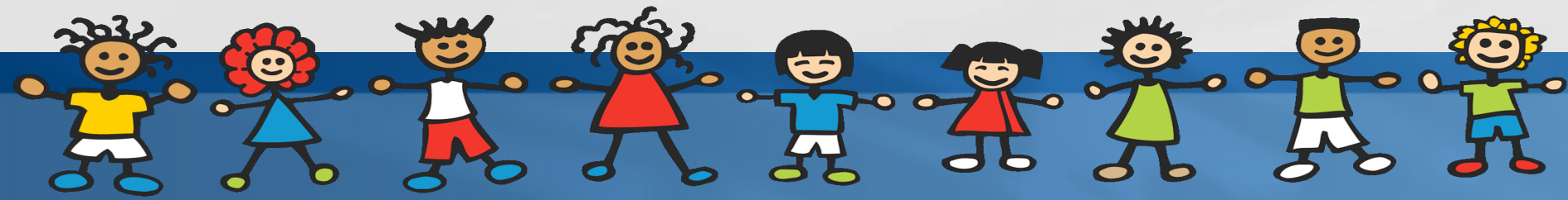
- Worry
- Fear
- Uncertainty
- Future for their child
- Public reaction to disability
- Tolerance
- Stigmatization



What do Parents Seek?

11

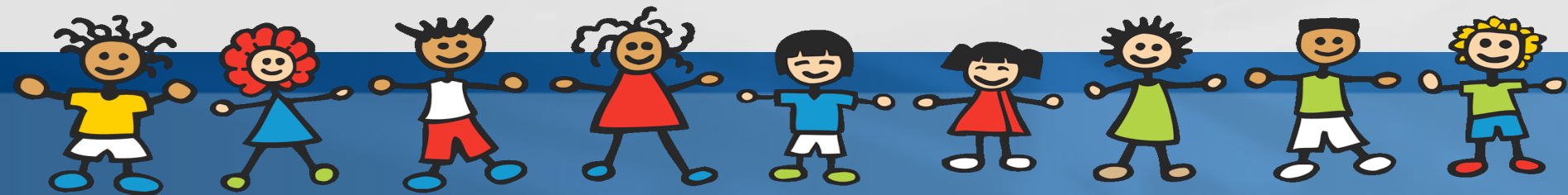
- Normalcy
- Certainty
- Information
- Control over stressors
- Partnerships with health care providers



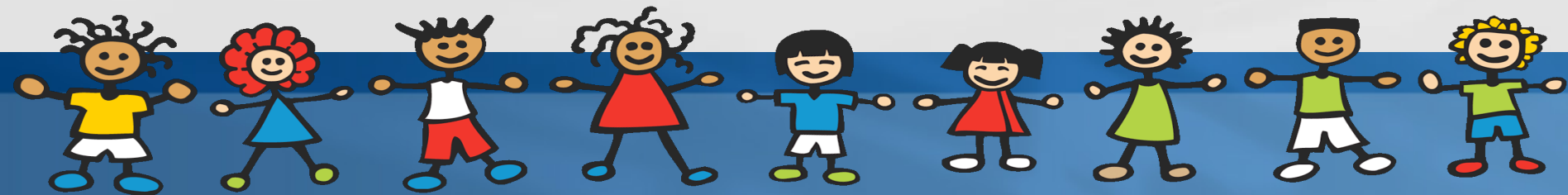
Parenting Stress

12

- It is stressful to care for a child with a chronic illness
- It is a family affair
- It is cross-cultural
- Successful management of illness is dependent on ability of parent to cope
- Coping is influenced by ability to resolve uncertainty in illness

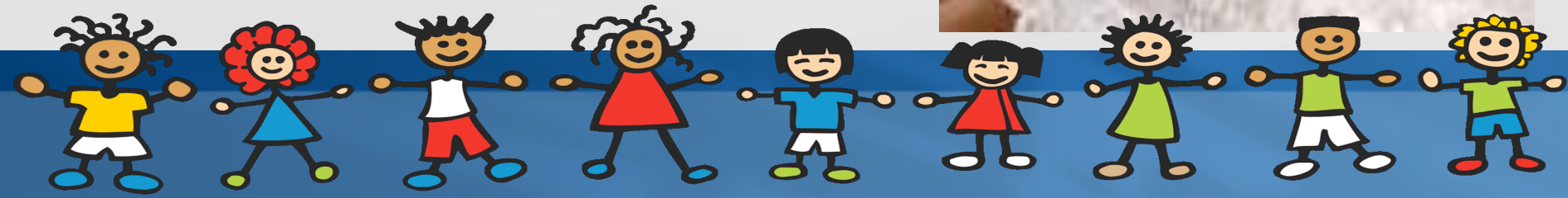


- Successful management of the child's illness depends on the ability of parent to cope
- Disease rareness, age of onset, loss of function, impact on mobility, course of illness, cognitive function, ability to communicate, visibility of illness
- Emotional support and positive coping influenced psychosocial adjustment of parents



What do we know about Mitochondrial Disease ? 14

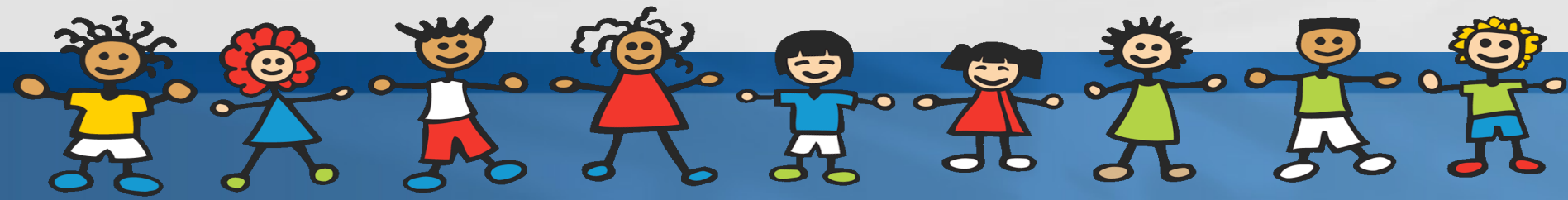
- Rare
- Childhood Disease
- Inherited
- Chronic neurodegenerative
- Life Limiting
- No cure
- No biological marker
- No Treatment
- Variety of clinical symptoms



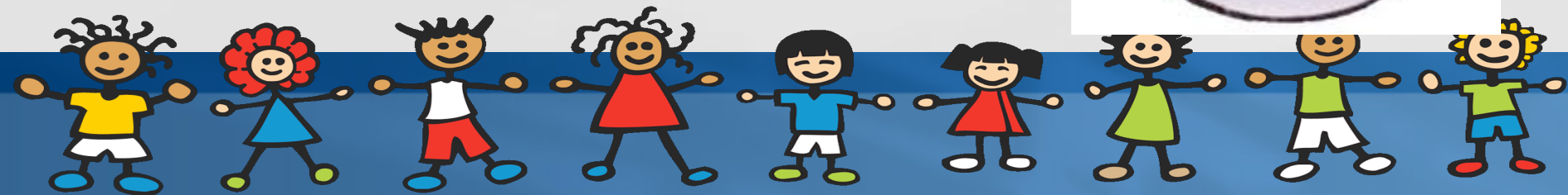
Unique Challenges of Mito

15

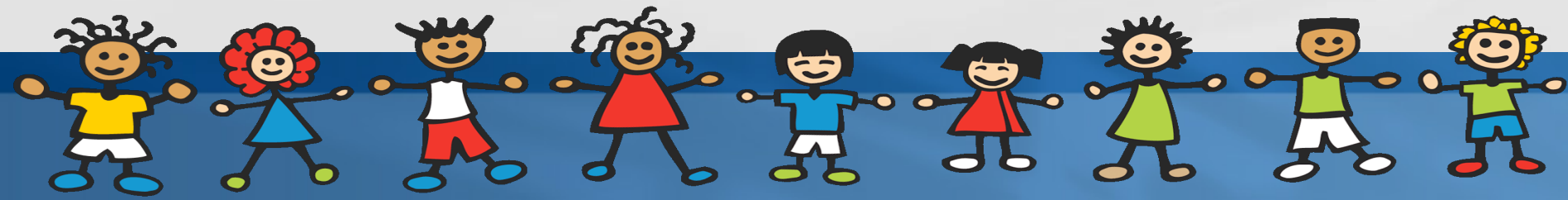
- Not a single chronic disease
- Spectrum of inherited disorders
- Unknown disease trajectory
- Unknown prognosis
- Neurodegenerative disease may look well at diagnosis, but deteriorate slowly or within a short period of time.



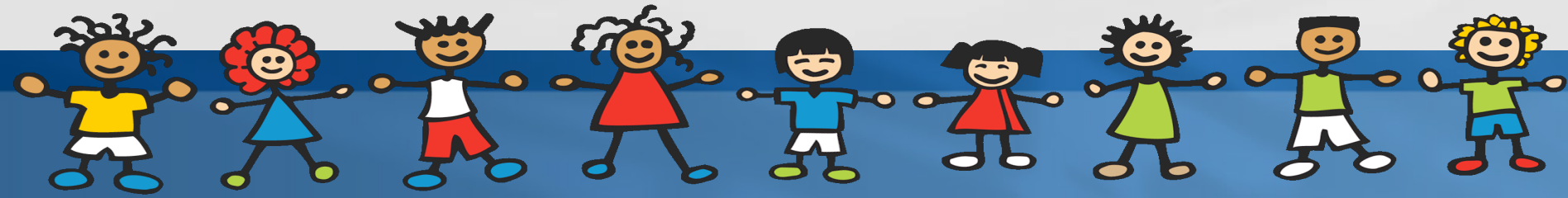
- Uncertainty of diagnosis, prognosis or disease progression in a complex health care setting
- Physically, emotionally, financially, socially and spiritually
- Expansion of Parent role
 - Medical experts
 - Care coordinators
 - Advocates
 - Teachers



- Medical care
 - Office visits
 - Hospitalizations
 - Special medical equipment at home/school
 - Wheelchairs, developmental delays, g-tubes, vision problems
- Physical care of the child
- Coordinating care with social services and the educational system

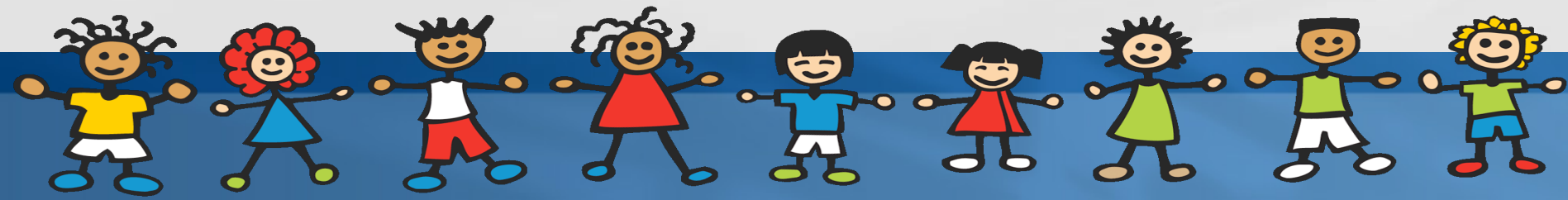


- Worry
- Fear
- Uncertainty of illness trajectory
- Variability of symptoms
- Diagnosis or not?
- Public reaction to child's disability
- Health care providers understanding needs
- Developmental lags of the child



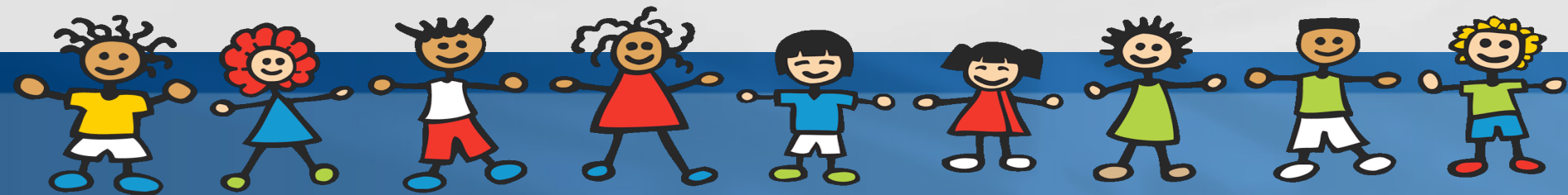
What We Know About Mito19

- Medical Science is taking lead role
- First documented case in 1962
- Diagnosis is difficult
 - No biological marker
 - Muscle biopsy
 - Genetic sequencing
 - Definite, Probable, Possible or Unlikely
- Treatment depends on symptoms
 - Mito cocktail



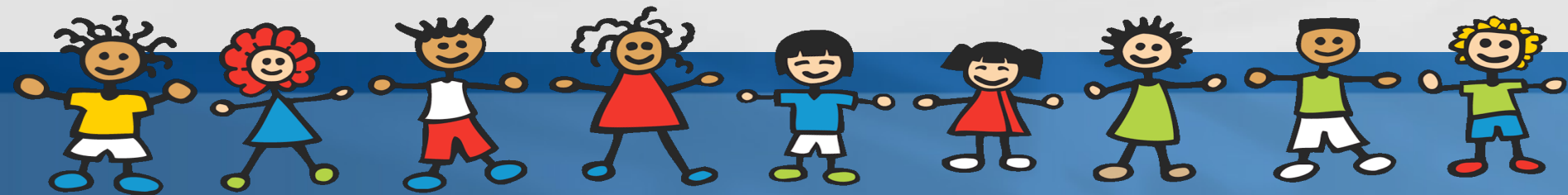
What We Know About Parents 20

- Gap in the number of studies done to understand needs of Mito parents
- Parents want information about:
 - symptoms, prognosis, life expectancy, genetics, coping, and support.
 - Health professionals lack information to give to parents



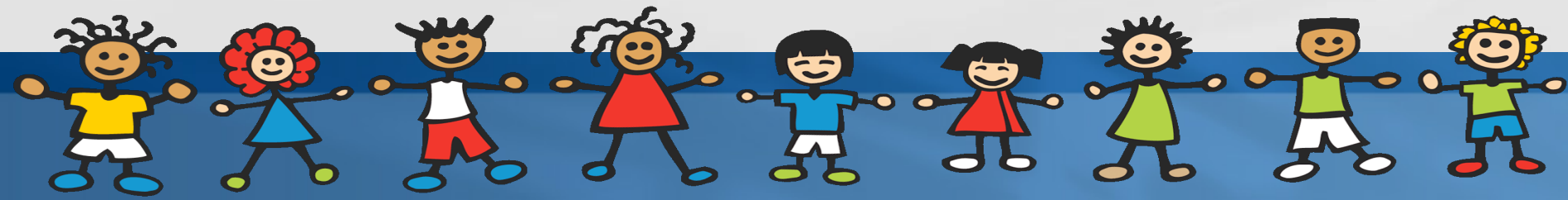
What We Know About Mito Moms 21

- Usually primary care giver
- Mothers experience greater psychological strain
- Mothers of children with Mito and PKU
 - Need of more health care services
 - More specialists
 - More hospitalizations
 - More financial burden
 - Out pocket expenses
 - Number of work days missed
 - More stress, strain and worry,



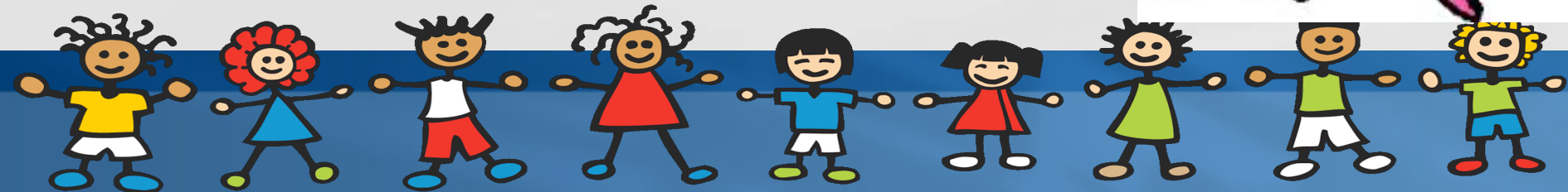
What We Know About Mito Moms 22

- Personality profiles of Mito mothers
- Elevates scores in
 - Hypochondria,
 - Hysteria
 - Paranoia
 - Depression
 - Anxiety
- Related to stress of uncertainty, and caregiving demands



What We Know About Mito Moms 23

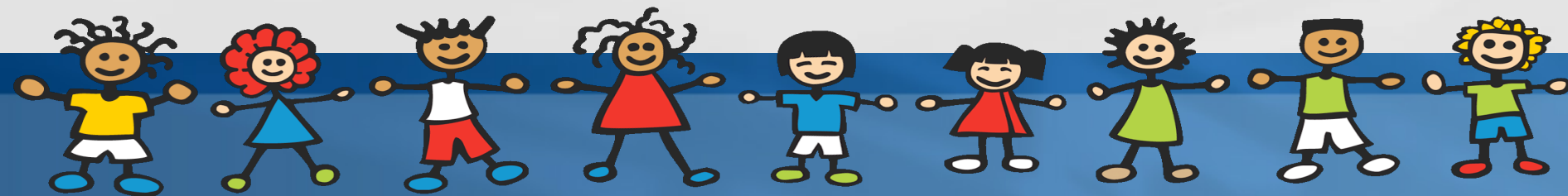
- Study from Korea
- Compare moms of children with epilepsy & Mito
 - Higher caregiver burden
 - Lower quality of life
 - Greater depression and anxiety
 - Guilt with maternal inheritance



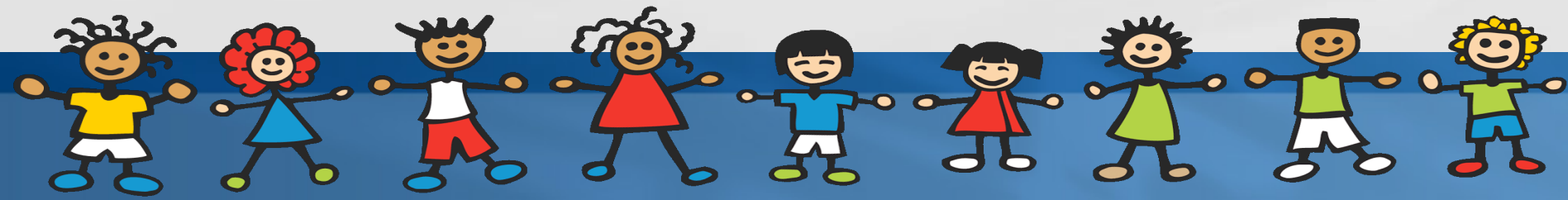
What Do We Know About Mito Stress and Coping?

24

- Caring for a child with Mito is stressful
- Parents want information about diagnosis, treatment, progression and genetic transmission
- Control over child's health care
- Support from family and friends predict quality of life
- Reliance on health care providers



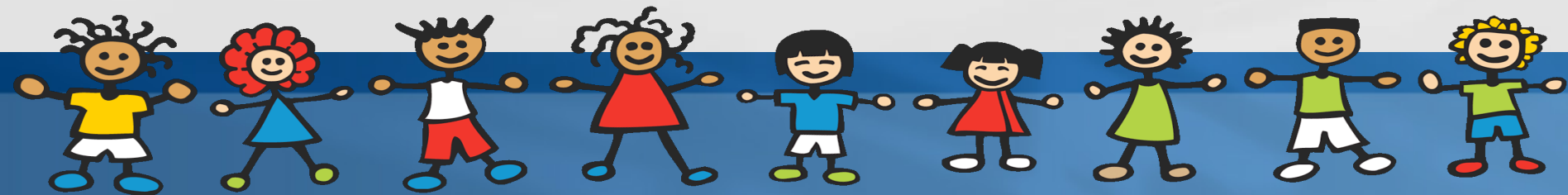
- Risk for emotional distress and family dysfunction
- Uncertainty associated with Mito
- Stress with uncertainty
- More research needed
- Parents want information, coaching, validation and competent health care providers



Welcome to the Mitochondrial Disease Parent Survey. Please answer the following questions.

- Please take and complete this survey and contribute to the growing body of knowledge around the needs of parents caring for a child with Mitochondrial disease.
- Mitochondrial Disease Parent Survey

https://wsunursing.qualtrics.com/SE/?SID=SV_cOnqRUyfTTHO5a5



Questions?

27



- Brenda Senger RN, MA, PhD(c)
- Brenda.senger4@gmail.com

