OCTOBER 19, 2026

HAPPINESS IS DOWN SYNDROME + TEAM IRON WILL + BEBE-PT

FOLLOWING YOUR OWN CURVE

UNDERSTANDING MOTOR DEVELOPMENT IN CHILDREN WITH DOWN SYNDROME



DOWN SYNDROME AWARENESS MONTH!

AGENDA

INTRODUCTIONS

BACKGROUND

MOTOR CURVES

SUPPORTING DEVELOMENT

CONSIDERATIONS

RESOURCES

COLLABORATION!

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INTRODUCTIONS



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Angela Fritz, PT, DPT, PCS, CNT

- NICU THERAPIST
- DHH
- ALLY AND ADVOCATE
- DOG MOM









INTRODUCTIONS

Happiness is Down Syndrome

- COMMUNITY
- RESOURCES
- EDUCATION
- SUPPORT





@HAPPINESSISDOWNSYNDROME

INTRODUCTIONS

Team Iron Will

- ADVOCACY
- SUPPORT
- CONNECTION

@TEAMIRONWILL21





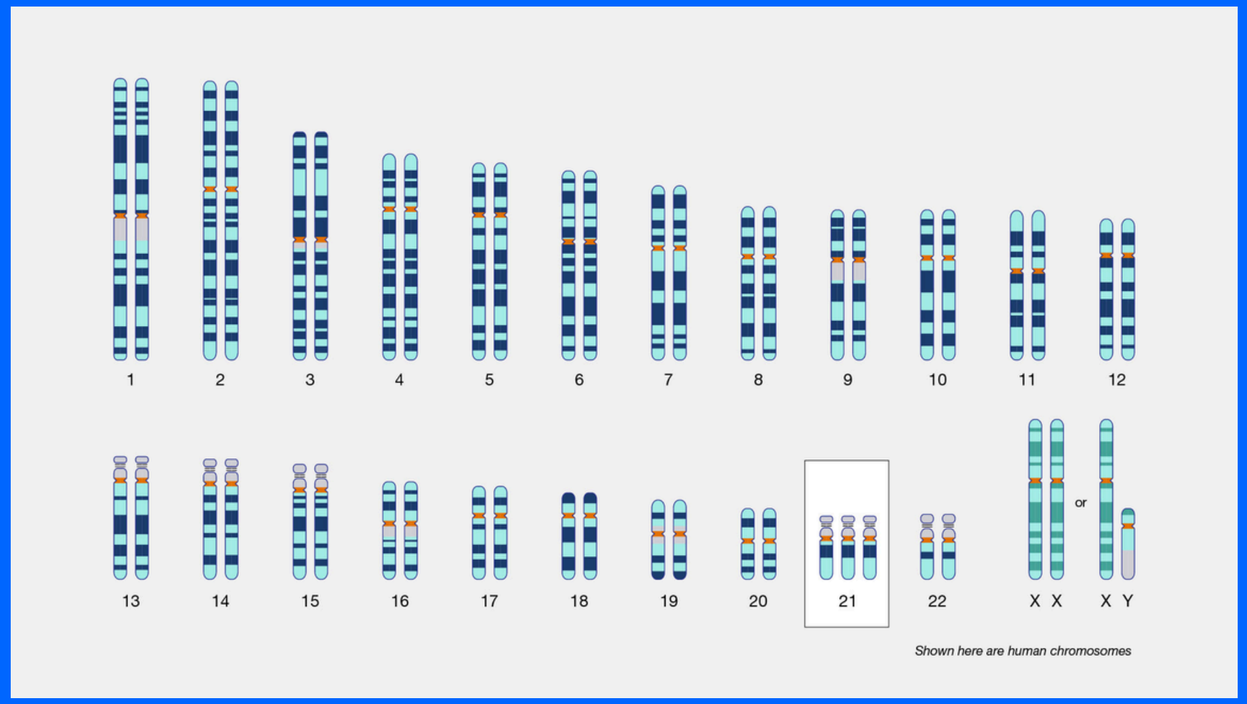
INTRODUCTIONS

Who are YOU?!

- PARENTS?
- CAREGIVERS?
- THERAPISTS?
- EDUCATORS?
- STUDENTS?
- ADVOCATES?



BACKGROUND

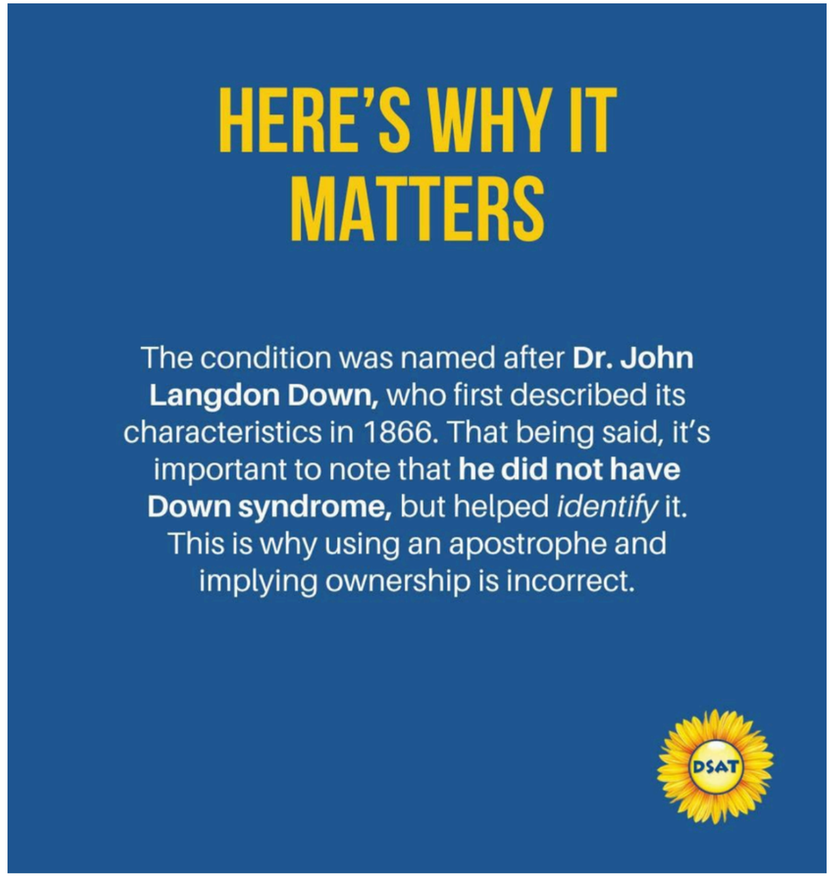


- The most common chromosomal condition, occurring in approx every 1 in 700 babies.
- It occurs when there is a partial or full extra copy of the 21st chromosome, resulting in trisomy 21, or Down syndrome (DS).
- There are different types of Down syndrome
  - Tristomy 21/Nondisjunction (95%)
  - Translocation (4%)
  - Mosaicism (1%)

HISTORY

- Down syndrome was first described In 1866 by John Langdon Down, but the term **Down syndrome** wasn't accepted until the early 1970s.
- In 1959, French pediatrician/geneticist Jerome Lejeune discovered the extra chromosome on the 21st.
- Historically, children with DS were institutionalized and segregated from society.





SECTION 504
OF THE REHABILITATION ACT

- Fought for by disabled activists led by Judy Heumann
- Signed into law in 1973
- Guarantees equal access, participation, and fair treatment for people with disabilities in entities like public schools, universities, and healthcare facilities that take federal funds.





CHILDREN WITH DOWN SYNDROME

CAN DO ANYTHING AND EVERYTHING!

COMMON CHARACTERISTICS

- LOWER MUSCLE TONE
- HYPERMOBILE JOINTS
- CERVICAL SPINE (NECK) INSTABILITY
- HIGHER RATES OF OBESITY
- DEVELOPMENTAL DELAYS



MILESTONE ANXIETY

- Milestone anxiety is real!
- Using milestones to identify delays or concerns early is crucial.
- Milestones are commonly outdated and vary depending on the baby
- Most milestone checklists are not inclusive.
- **It’s important to delight in each baby’s individual development!**



Baby Development • 2/19/21

MUSINGS ABOUT MILESTONES

Milestone anxiety is a real thing! In this post we break down the importance of using milestones as a guide, not a checklist, and to reference them in order to identify delays and guide intervention, but also remembering to delight in each baby’s individual development!

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CDC UPDATES

- In 2022 the CDC and the AAP collaborated to update the developmental milestone checklist for the first time since 2004.
- The group included 13 pediatricians
- No therapists (OT/PT/SLPs) or educators were included as authors of the study and updates.



UPDATES TO THE CDC MOTOR MILESTONES

2004	2022
Independent sitting at 6 months	**Independent sitting at 9 months**
Crawling at 9 months	**Crawling NOT included**
Walking at 12 months	**Walking at 18 months**

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PRO'S AND CON'S TO THE CDC MILESTONE UPDATES

Pro's	Con's
Updates haven't been made in almost 2 decades	There is controversy about the updates
13 pediatricians combined expertise to create them	No PT/OT/SLP/Educators were consulted
Milestones now indicate when 75% of children meet them	Concerns about delaying intervention and encouraging "wait and see"

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ASSESSMENTS

- Gross Motor Function Measure (GMFM)
  - Established motor curves for children with DS
- Alberta Infant Motor Scales (AIMS)
- Hammersmith Neonatal Neurological Examination (HNNE) / Hammersmith Infant Neurological Examination (HINE)
- Muscle tone, reflexes, responses
- Bayley-4
  - Validated in children with DS and other special groups



MOTOR MILESTONES

- Average age of aquisition for children with DS:

MOTOR GROWTH CURVES FOR DOWN SYNDROME, Palisano 499

Table 5: Predicted Probability of Achieving Gross Motor Functions Across Ages for Children With DS Based on Logistic Regression

Millestone	Predicted Probability (%) of Achieving Motor Milestone								
	Age (mo)								
	6	12	18	24	30	36	48	60	72
Rolling	51	64	74	83	89	93	97	99	100
Sitting	8	78	99	100	100	100	100	100	100
Crawling	10	19	34	53	71	84	96	99	100
Standing	4	14	40	73	91	98	100	100	100
Walking	1	4	14	40	74	92	99	100	100
Running	1	2	3	5	8	12	25	45	67
Climbing step	0	0	1	1	3	5	18	46	77
Jumping forward	0	0	0	1	2	5	18	52	84

PALISANO, ET AL (2001)

Milestone	Range for Children with Down Syndrome
GROSS MOTOR	
Sits Alone	6 – 30 Months
Crawls	8 – 22 Months
Stands	1 – 3.25 Years
Walks Alone	1 – 4 Years
LANGUAGE	
First Word	1 – 4 Years
Two-Word Phrases	2 – 7.5 Years
SOCIAL/SELF-HELP	
Responsive Smile	1.5 – 5 Months
Finger Feeds	10 – 24 Months
Drinks From Cup Unassisted	12 – 32 Months
Uses Spoon	13 – 39 Months
Bowel Control	2 – 7 Years
Dresses Self Unassisted	3.5 – 8.5 Years

NATIONAL DOWN SYNDROME SOCIETY

CONSIDERATIONS

STRENGTHENING

ORTHOTICS/EQUIPMENT

ADAPTATIONS

POSTURAL STABILITY

POSITIONING

POSITIONING

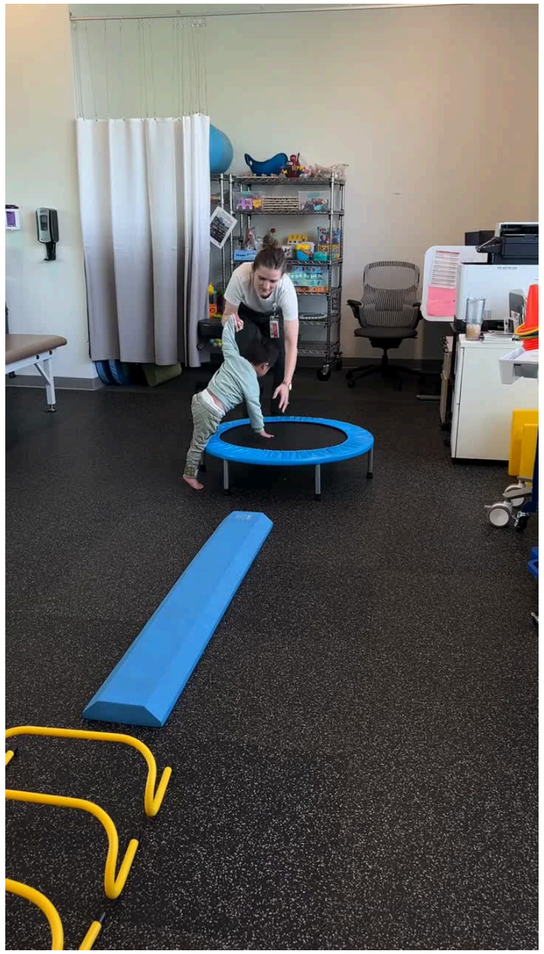
- Start tummy time right away!
- Promote midline postures and alignment
- Protect head/neck during activity

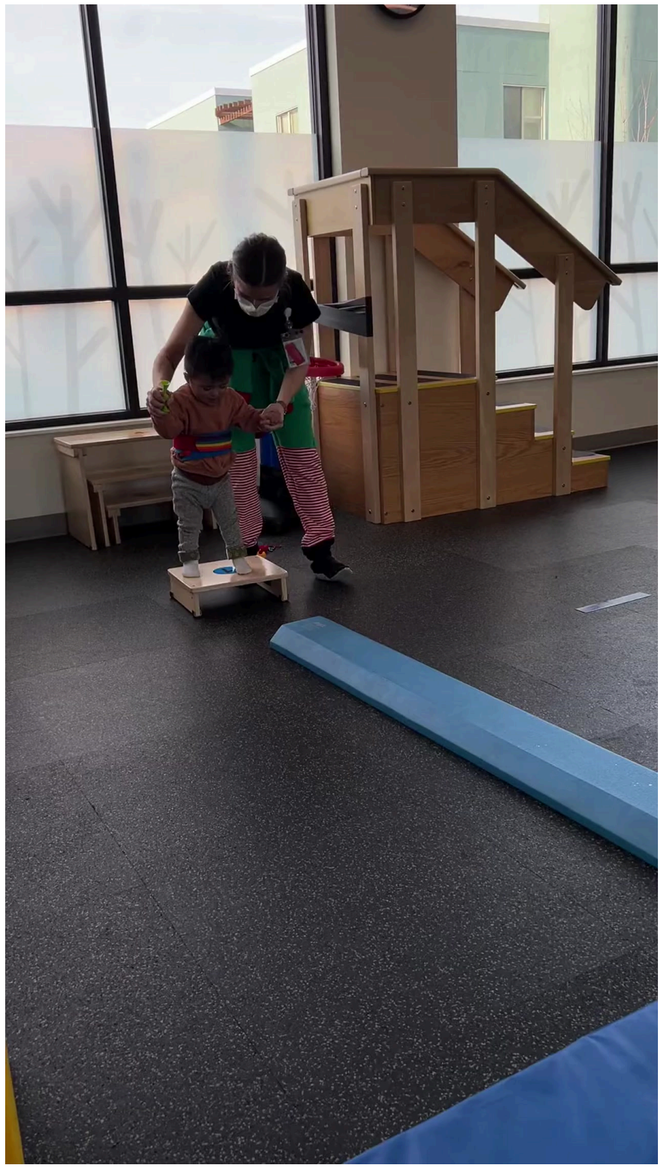


STRENGTHENING

- Extra repetitions
- Weights
- Power
- Anti-gravity strengthening





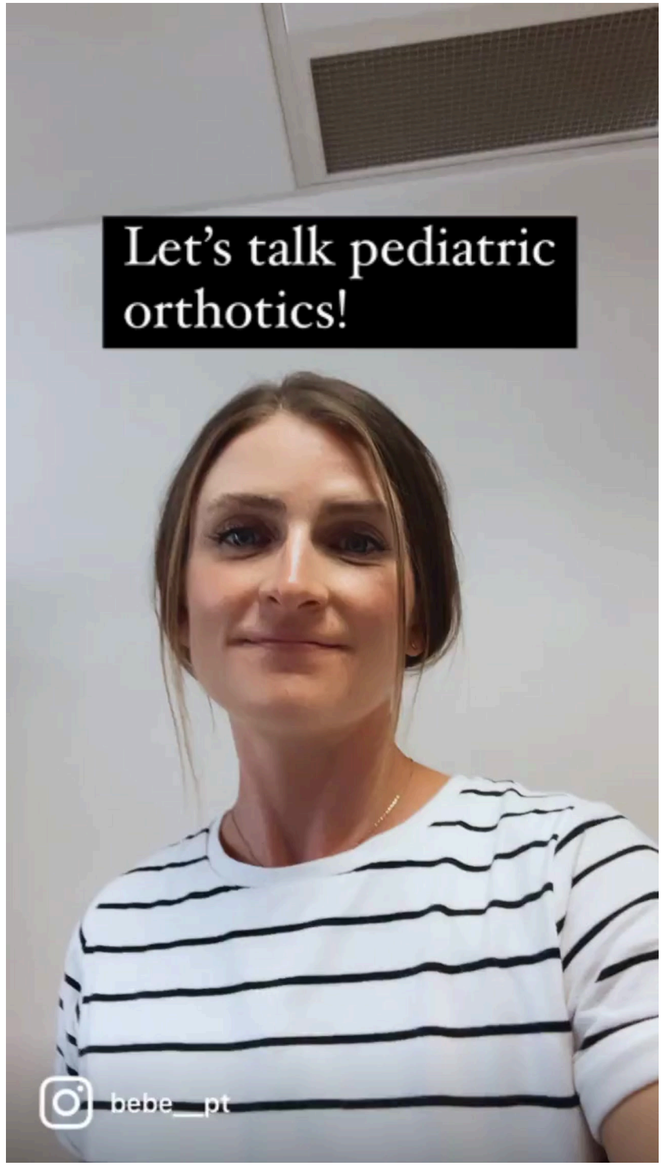


KICKING GYM

- Children with DS had significantly decreased complex kicking movements compared to their typically developing peers
- Kicking in infancy is significantly correlated with earlier onset of walking
- Infants with DS who participated in a kicking gym protocol had increased frequency of kicking movements, and earlier onset of walking



Protocol: 20 min/day, 5 x week



ORTHOTICS

- Do an objective gait assessment
  - Navicular drop
  - Arch index
- Choose the right option with a professional
  - FO vs SMO vs AFO
- Use with supportive shoes
- Ensure barefoot time for foot/ankle strengthening!



CASCADE DAFO

POSTURAL STABILITY

- Core strength
- Balance
- Spio suit









ADAPTATIONS

- Early mobility
- Music therapy!
- Virtual reality training
- Standers and walkers





Thread 1

Moderate

Bocce game intervention significantly improves gross motor skills in students with T21 over 4 weeks (p = 0.003) Firdaus 2023 .

Moderate

Virtual reality-based therapy stimulates global motor skills, balance, and body scheme in children with T21 across 18 reviewed studies Boato 2022 .

Moderate

Music as an adjunct in occupational therapy increases participation and independence in daily motor tasks for a child with T21 De Oliveira 2024 .

COLLABORATION

ADVOCACY

TRUSTED HEALTHCARE TEAM

PEER SUPPORT

RESOURCES



LET'S HEAR IT FROM THE PARENTS!

-"Positive and comfortable environment–don't let the diagnosis be the elephant in the room! Parents need nuggets of hope"

-"Stay current on new developments in DS research/therapy"

-"Be inclusive with language and teachings when working with parents"

-"Communication and education on how to best support development and achieve goals"

-"You will have a huge impact on kiddos and their families that is long-lasting."

-"Let the child lead and show us where to go–not the diagnosis"

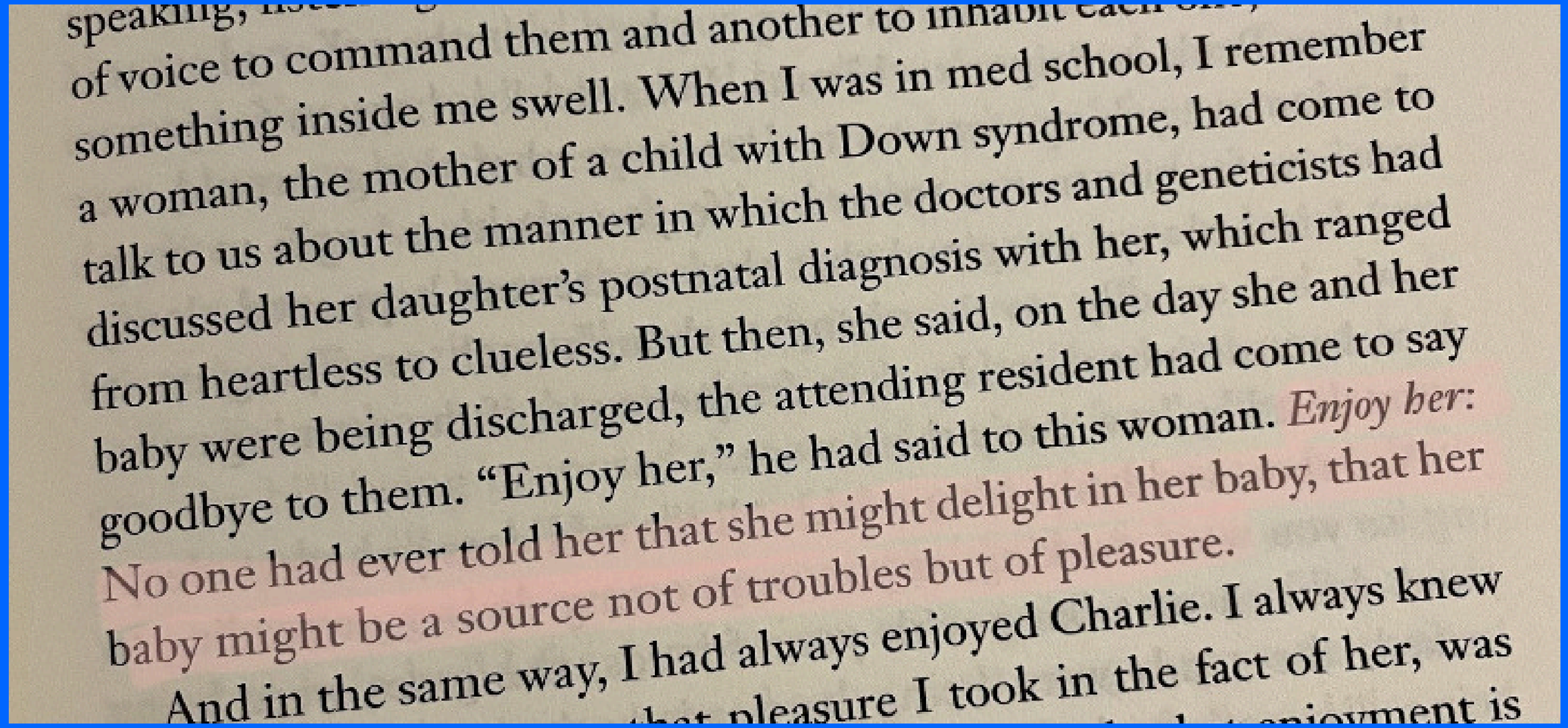
-"There is a lot of trauma and grieving involved with new diagnosis. Be aware that this is a tender time for families"

-"Embrace the child for exactly who they are. Weave goals into what the child is interested in"

-"Don't react with pity, help celebrate the joy of the child"



EXCERPT FROM "TO PARADISE" BY HANYA YANAGIHARA



speaking, listening
of voice to command them and another to inhabit each other
something inside me swell. When I was in med school, I remember
a woman, the mother of a child with Down syndrome, had come to
talk to us about the manner in which the doctors and geneticists had
discussed her daughter's postnatal diagnosis with her, which ranged
from heartless to clueless. But then, she said, on the day she and her
baby were being discharged, the attending resident had come to say
goodbye to them. "Enjoy her," he had said to this woman. *Enjoy her:*
No one had ever told her that she might delight in her baby, that her
baby might be a source not of troubles but of pleasure.

And in the same way, I had always enjoyed Charlie. I always knew
that pleasure I took in the fact of her, was
enjoyment is

RESOURCES

-NATIONAL DOWN SYNDROME SOCIETY

-FACEBOOK/INSTAGRAM COMMUNITIES

- @HAPPINESSISDOWNSYNDROME
- @TEAMIRONWILL
- @BEBE__PT



national down syndrome society

ndss®

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QUESTIONS? COMMENTS? FEEDBACK?

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