



**REGRESSION IN DOWN
SYNDROME-WHAT IS IT AND
WHAT DO I DO ABOUT IT?**

Disclaimer

1. We will be presenting our own clinical experience, and this is reflected in the literature, but there is not a robust evidence base in the literature yet
2. Access to assessment and treatment can vary widely, and this may determine what treatment is available. In general, DSRD is not widely recognized or understood outside of DS clinics, so ability to work with local services and practitioners is necessary to assist them in understanding the importance of recognizing and treating this condition
3. As medical practitioners, we cannot offer specific patient advice in this forum. We are happy to answer questions about general scenarios but ask that individual's details are not specified.

Speakers

Eileen Quinn, MD (Overview, diagnostic criteria, case example)

Cathy Franklin, MD (ECT, psychiatric medications, other treatments)

Jon Santoro, MD (Immune modulation-IVIg)

Lina Patel, PsyD (Behavioral interventions and supports)

George Capone, MD (Moderator)



DSRD: CASE EXAMPLE

Eileen A. Quinn, MD

Developmental and Behavioral Pediatrics

U. of Toledo College of Medicine and Life Sciences

Toledo, OH



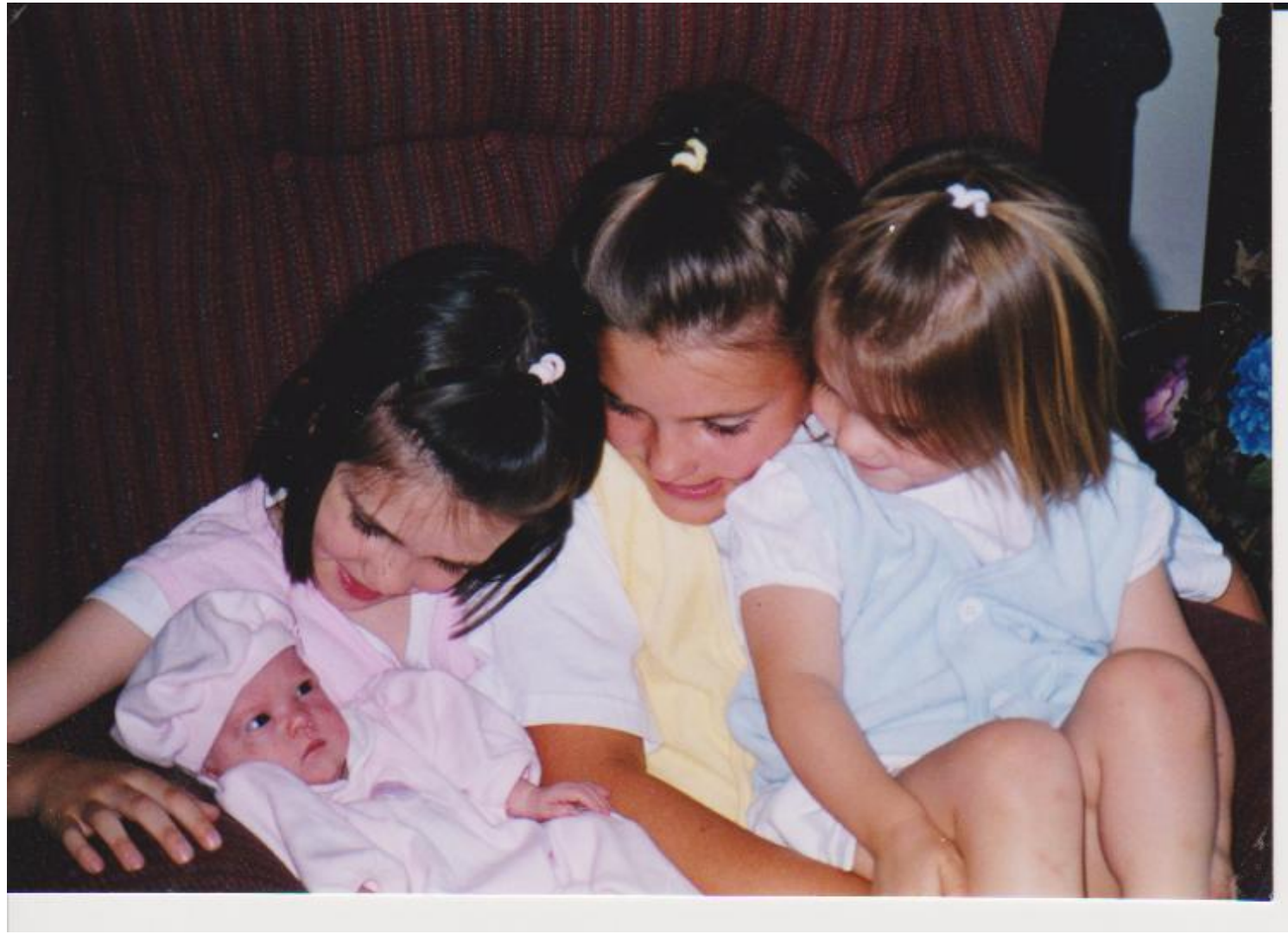
COLLEGE OF MEDICINE
AND LIFE SCIENCES

THE UNIVERSITY OF TOLEDO

Past Medical History

- Born 7 weeks early, weighing only 2# 11 ounces
- Diagnosed with hypothyroidism at birth
- Echocardiogram revealed a heart defect (Tetralogy of Fallot)
- Discharged home at 6 weeks of age





Past Medical History

- Heart defect repaired at 6 months
- Hospitalized at age 2 years and again at age 3 years with RSV pneumonia
- Eye surgery at age 8 years
- Sleep study revealed obstructive sleep apnea at age 9 years which resolved with a tonsillectomy and adenoidectomy





School

- Fully included in regular classroom preschool through 5th grade
- With modified curriculum, engaged in classes
- 5th grade IEP: “Sara has a sparkling personality...she spontaneously invites friends to join her at recess...She makes the class laugh everyday...WONDERFUL sense of humor”

Home

- Participated in recreational soccer league, swim team, Girl Scouts, dance class and karate
- Favorite activities included bike rides, Wii, trying to keep up with her older sisters

Before regression video #1

Before regression video #2



Several months prior to regression

- Transitioned to Middle School
- Lost her connections to her “best friends”
- Pulled out to Special Ed class – exposed to shouting, threats
- Never spoke of problems, but notes were found that she wrote to her teacher detailing the incidents and her distress over them
- Mild behavioral changes – more irritable, lethargic, spending more time alone

Regression and Behavioral Changes

- Insomnia
- Withdrawn
- Avoided eye contact
- Stopped talking
- Irritable
- Emotionally labile
 - Crying episodes
 - Outbursts of laughing

Regression and Behavioral Changes

- Exaggerated startle reflex
- Sensitive to touch
- Fascination with lights
- Repetitive behaviors

Regression and Behavioral Changes

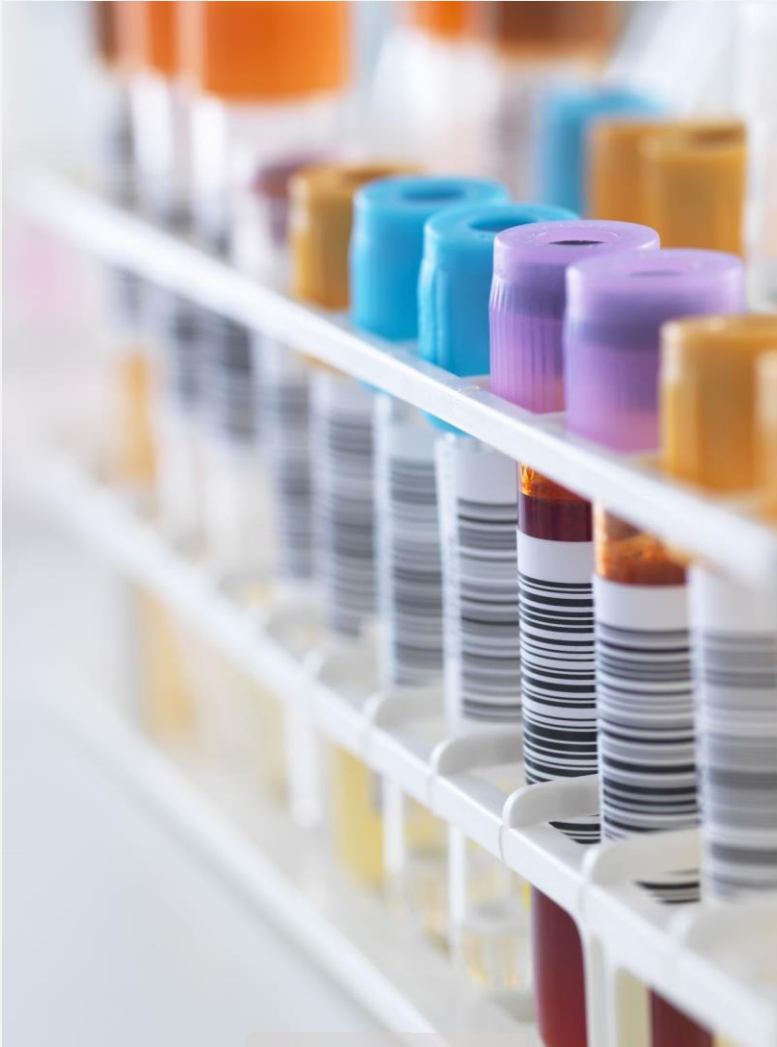
- Voracious appetite
- Poor concentration
- Incontinence
- Locking self in bathroom at school for much of the day

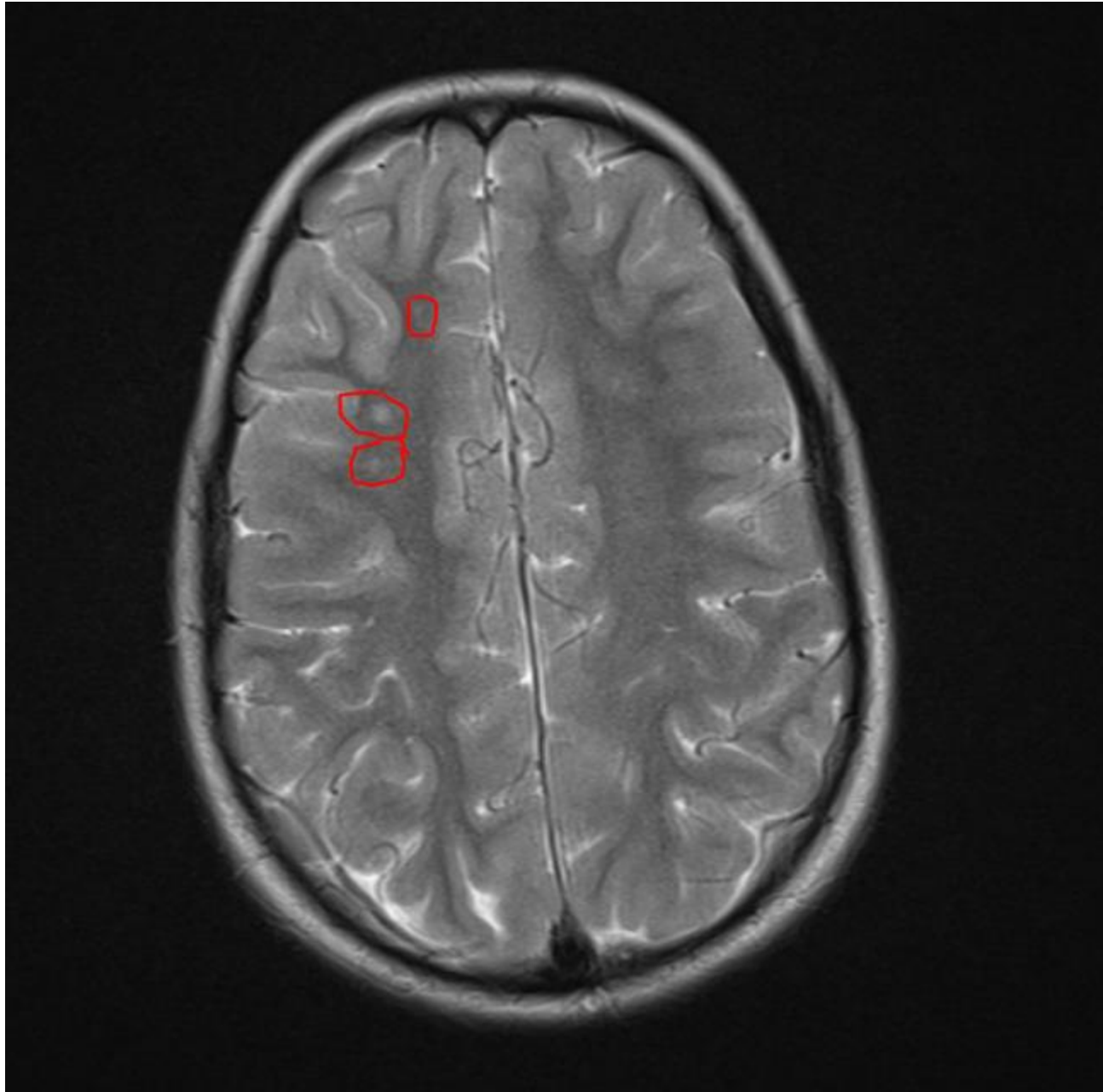
Regression video #1

Regression video #2

Medical Workup - Negative

- EEG
- Sleep Study
- Hearing and vision tests
- Blood tests (CBC, chemistries, celiac screen, ASO titers, thyroid antibodies)





Diagnosis

- Three months into regression she was evaluated by a child psychiatrist and a therapist experienced with children with disabilities. Based on her symptoms and notes she had written, she was diagnosed with Posttraumatic Stress Disorder with Dissociation
- Two years into regression a second opinion was sought from a child psychiatrist but no further tests or treatments were suggested
- Three years into regression a third opinion was sought from a child psychiatrist who had experience with regression in adolescents with DS and she was diagnosed with catatonia.



Treatment Trials

Medications

- SSRIs (fluoxetine, escitalopram, fluvoxamine)
- Antipsychotics (risperidone, aripiprazole)
- Benzodiazepines (lorazepam, alprazolam)
- NMDA receptor antagonists (memantine, Nuedexta)

Transcranial Magnetic Stimulation

- 4 week course




Consensus DSRD Diagnostic Criteria

Santoro JD, et al. Assessment and Diagnosis of Down Syndrome Regression Disorder: International Expert Consensus. Front Neurol. 2022 Jul 15

Category	Criteria	Possible DSRD	Probable DSRD
Symptom onset	Onset of new neurologic, psychiatric, or mixed symptoms over a period of <12 weeks in previously health individual with Down syndrome	Yes	Yes
Clinical evidence of neurologic dysfunction	<ol style="list-style-type: none"> 1. Altered mental status or behavioral dysregulation <ul style="list-style-type: none"> - Anorexia/decreased oral intake or hyperphagia - Confusion/disorientation - Inappropriate laughter - Encephalopathy 2. Cognitive decline <ul style="list-style-type: none"> - Apathy - Abulia and/or avolition - Acute memory impairment (including new difficulty with recall) 3. Developmental regression with or without new autistic features <ul style="list-style-type: none"> - Social withdrawal - Loss of previously developmental acquired milestones - Inability to perform activities of daily living - Stereotypy - Rigidity around routine changes - Decreased eye contact 4. New focal neurologic deficits on examination and/or seizure 5. Insomnia or circadian rhythm disruption 6. Language deficits <ul style="list-style-type: none"> - Expressive and/or receptive aphasia - Global aphasia (mutism) - Whispered speech 7. Movement disorder (excluding tics)* <ul style="list-style-type: none"> - Catatonia - Bradykinesia - Freezing - Gait disturbance 8. Psychiatric symptoms <ul style="list-style-type: none"> - Anxiety - Delusions or hallucinations - Derealization/depersonalization - Obsessive compulsive tendencies - Aggression/agitation 	>3 symptom clusters present	>6 symptom clusters present
Exclusion of other etiologies	Reasonable exclusion of alternative causes of regression including other systemic and central nervous system disorders. Other primary psychiatric disorders are also considered exclusionary	Yes	Yes

*Must be included as one of the symptom clusters for possible or probable diagnosis.



Down Syndrome Regression Disorder Symptoms Checklist (NDSS)

- <https://ndss.org/resources/regression-down-syndrome>
- There are eight total symptom “clusters”:
 1. Behavioral changes
 2. Changes in thinking
 3. Loss of functional and social skills
 4. New seizures or neurological deficits
 5. Difficulty sleeping
 6. Language difficulties
 7. Irregular movement
 8. Mental health or psychiatric symptoms

DSRD Symptoms

1. Behavioral Changes
 - Eating much more or less than usual
 - Confusion or disorientation
 - Laughing or crying at inappropriate times
 - Frequent changes in mood or rapid fluctuations between happiness, sadness or anger
2. Changing in Thinking and Processing of Information
 - Decreased visible emotions and empathy
 - Lack of motivation or lack of engagement
 - Difficulty starting or finishing tasks
 - Worsening memory

DSRD Symptoms

3. Loss of Functional and Social Skills
 - Loss/worsening of previously learned skills (self-feeding, toileting, dressing, etc.)
 - Decreased social interaction with friends, family, classmates, or coworkers
 - Decreased eye contact
 - Repetitive hand or body movements with no clear purpose
4. New seizures or neurological deficits (weakness, slurring of speech, etc.) determined by a physician

DSRD Symptoms

5. Difficulty sleeping or sleeping at irregular times
6. Language Difficulties
 - Difficulty producing speech or trouble reading and understanding speech
 - No longer using speech or speaking only in a whisper
7. Irregular Movements
 - Lack of movement sometimes with stiff and rigid muscles
 - Moving very slowly or using an unusual walk or run gait pattern

DSRD Symptoms

8. Mental Health Symptoms

- New or worsened anxiety
- Delusions (untrue beliefs) or hallucinations (seeing things that are not there)
- Derealization (feeling detached from surroundings) or depersonalization (feeling of observing oneself from outside of the body)
- Obsessive compulsive tendencies like lining up items, only talking about specific topics of interest, and difficulty tolerating changes in routine
- Aggression or agitation toward others

Psychiatric Approach to DSRD

Dr Cathy Franklin

Psychiatrist

Director, Mater Intellectual Disability and Autism Service (MIDAS)

Director, Qld Centre of Intellectual and Developmental Disability
(QCIDD)

Presentation outline

PSYCHIATRIC ASPECTS OF ASSESSMENT

- Psychiatric conditions relevant to DSRD

PSYCHIATRIC ASPECTS OF MANAGEMENT

- Overview of DSRD management
- Psychiatric medications
- ECT, TMS





THE UNIVERSITY
OF QUEENSLAND
AUSTRALIA

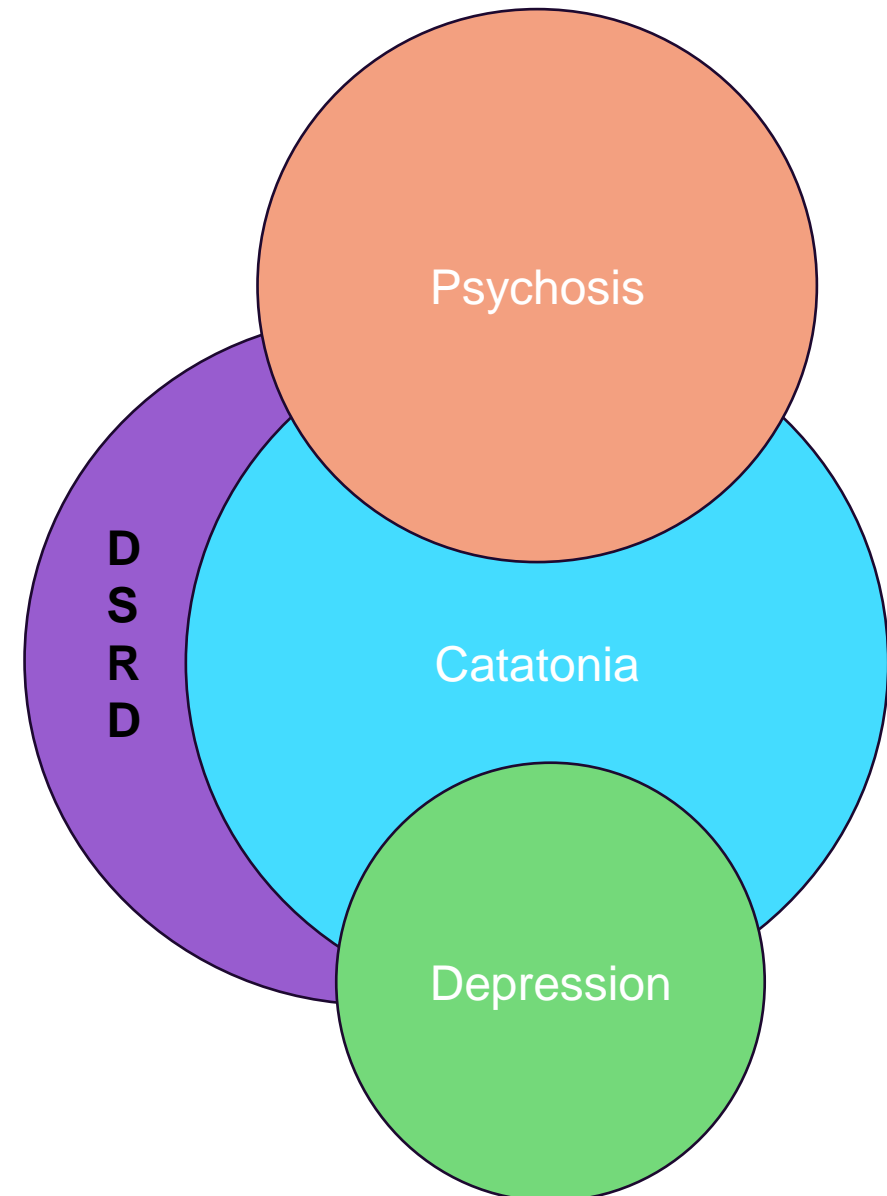
CREATE CHANGE

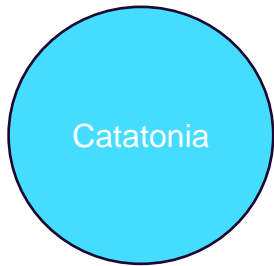
Psychiatric Aspects of Assessment

Psychiatric symptoms in DSRD

- Catatonia is very common in DSRD
- Psychosis is fairly common
- Depressive symptoms also occur

NB: To psychiatrists unfamiliar with DSRD, the symptoms can sound like major depression or psychosis, but fail to respond to medications if those diagnoses are the sole focus of treatment.





“Catatonia is a disorder of movement and control. It can make it hard for your brain to tell your body what to do.”

- It can make your body very slow, or even completely stuck and unable to move at all. (**stupor**)
- Your body might get stuck in unusual positions (**posturing** – self; **catalepsy** – by examiner)
- Your body might move differently, or feel stiff (**rigidity, waxy flexibility, gegenhalten**)
- You might have trouble speaking or stop speaking altogether. (**mutism**)
- Your thoughts, speech and body might get stuck on the same thing. (*Thoughts and speech: **verbigeration** – stuck record, **perseveration** – returning to same topic*) (*Body: **ambitendency***)
- Your body might make unusual movements that you can't control. (**Mannerisms, stereotypies, tics**)
- You might smile (**grimacing**), laugh or cry for no reason.
- It might be **hard to chew or swallow**.
- It might be hard to do your usual activities, so you might need more help with things like showering, dressing, toileting and moving.

Catatonia

Interview Questions for Families

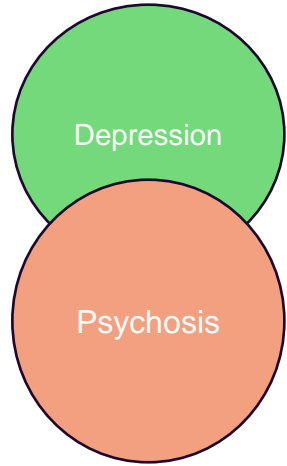
Does the person ever

- get stuck in one position – if so, how long for? (*posturing*)
- get stuck in the middle of a movement – (*ambitendency*)
- need help getting started with a movement e.g. feeding self with cutlery, taking a step.
- get stuck in “loops” of behaviour? (*perseveration*)
- Have trouble crossing thresholds e.g. through doorways or up/down stairs
- Repeat other’s speech or movements? (*echolalia / echopraxia*)

Have you noticed:

- decreased speech / communication (*mutism*)
- increased slowness – e.g. How long does it take to eat breakfast now (compared to previously)?; How long does it take to get dressed now (compared to previously)? (*bradykinesia*)
- unusual movements – eye rolling back, repetitive frequent movements (*stereotypy*) or odd ways of doing usual behaviours (*walking backwards*, stepping sideways) (*mannerisms*)
- unusual facial expressions e.g. grimacing (*grimacing*)
- abnormal staring (*staring*)
- changing handed-ness (e.g. was always left but now right handed)
- periods of rushing around, agitation without obvious trigger (*agitation*)

NB: Inappropriate laughing and crying can also occur and be mistaken for hallucinations



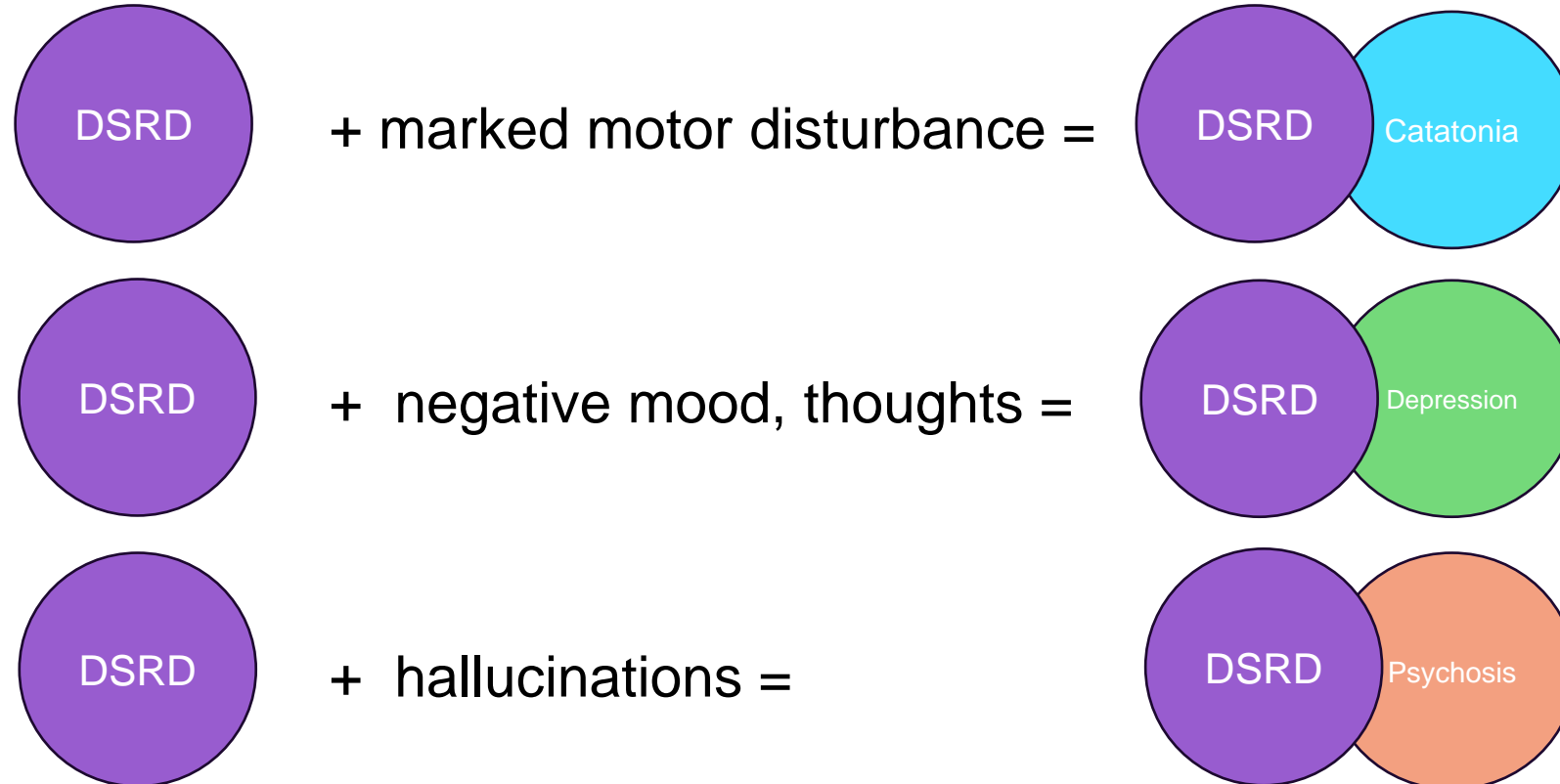
Is there depression or psychosis?

DEPRESSION – Mood changes	PSYCHOSIS – Hallucinations, Delusions
Sad or irritable mood	Hallucinations*
Loss of interest or pleasure in activities	Delusions
Insomnia	Insomnia
Weight gain or loss	Weight loss
Worthlessness, guilty thoughts	Disorganized speech or thought
Agitation	Agitation

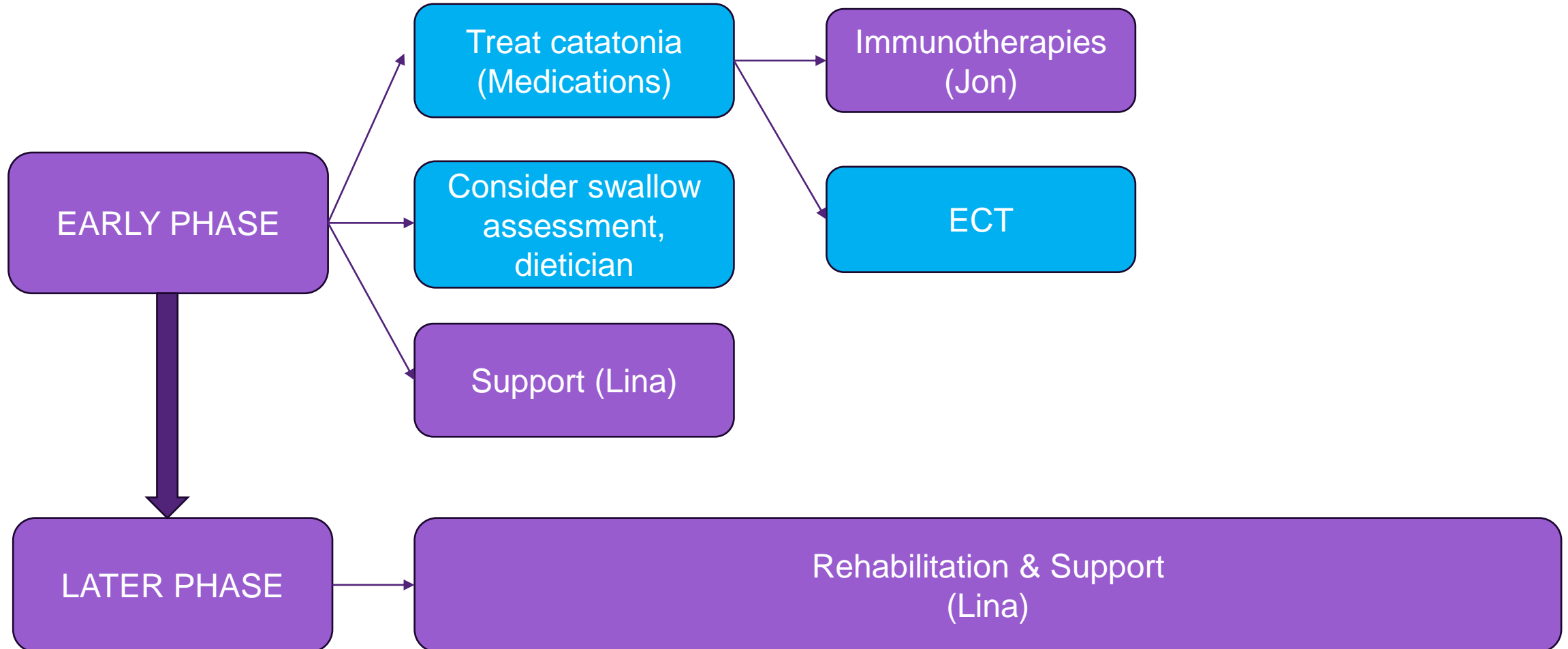
Comparison of Psychiatric Conditions Associated with DSRD

DEPRESSION	PSYCHOSIS	CATATONIA
Sad or irritable mood	Hallucinations*	Slowness / 'Stupor' (no movement and not reacting to environment)
Loss of interest or pleasure in activities	Delusions	Mutism
Insomnia	Insomnia	Insomnia
Weight gain or loss	Weight loss	Weight loss
Worthlessness, guilty thoughts	Disorganized speech or thought	Negativism (opposition or no response to instructions)
Agitation	Agitation	Agitation
Can be complicated by psychosis or catatonia	Can be complicated by catatonia	Posturing, catalepsy

Quick guide: More than one condition?



Management of DSRD





THE UNIVERSITY
OF QUEENSLAND
AUSTRALIA

CREATE CHANGE

Psychiatric Treatments for DSRD

Management of Psychiatric Symptoms in DSRD

Catatonia

- **Monitor oral intake, urination (may become an emergency if stop eating, drinking, passing urine)**
- Medication called lorazepam (“Ativan”) is first-line
- Other medications including atypical antipsychotics are second-line
- Some anti-dementia drugs have also been reported to have some success in DSRD
- Other treatments: ECT (highly effective), TMS (case reports in DSRD)

Psychosis

- Antipsychotic medication

Depression

- Antidepressant medication



THE UNIVERSITY
OF QUEENSLAND
AUSTRALIA

CREATE CHANGE

Psychotropic Medications

Lorazepam

- First-line treatment in catatonia: more effective than other benzodiazepines (e.g. diazepam (Valium), clonazepam (Rivotril))
- Start at a low dose and build up according to side effects
- Instant effect once you hit the right dose
- Tolerance has not been a problem in any of my patients with catatonia (n=20-25)
- **DON'T** stop suddenly (risk of withdrawal) and **DO** store in a safe and secure place!

Anti-psychotics and anti-depressants

- Use half normal dose in people with Down syndrome to achieve same result
- Try to avoid any that cause weight gain

Antipsychotics – My Experience

- Can improve clinical features of DSRD even when there are no signs of psychosis, e.g. as an "add-on" to lorazepam
- Current first-line choice is lurasidone (less weight gain, less sedation) – but I have seen a few cases of aggressive food-seeking necessitating change to another medication
- Most people with DSRD don't tolerate aripiprazole or brexpiprazole although these have better side-effect profiles for weight
- Risperidone can be effective
- Olanzapine is most effective but will cause significant weight gain so is reserved for desperate situations

Antidepressants

- Only useful where significant anxiety or depressive symptoms present
- My experience - I have had some patients develop anxiety symptoms (panic attacks) that we initially thought was catatonic excitement – responded well to SSRI treatment
- SSRI's are first line, I have not found additional benefit with SNRI's or Tricyclic antidepressants



Neurostimulation (ECT, TMS)

ECT (Electroconvulsive Therapy)

- Involves delivering an electrically induced seizure to an anaesthetised patient



Brief general anaesthetic – patient is totally asleep and given muscle relaxant to prevent muscle contraction

Machine administers specific dose of electrical charge through electrodes

Seizure lasts up to 1 minute, monitored on EEG trace

Patient is awake after a few minutes

- Affects memory at time of treatment
- Large-scale studies suggest no lasting memory impairment
- Reserved for cases where other treatments don't work
- Highly effective treatment at getting someone well but not at preventing relapse
- Initial treatment 3 times / week for 4 weeks, then increasingly spaced out, may need fortnightly or monthly treatments for 1-2 years
- ***Access and approval procedures vary from state to state, may be very difficult in some areas, all access requires psychiatric team that recognise DSRD/catatonia



TMS Trans-magnetic stimulation

- Magnetic fields are used to stimulate the underlying brain
- A magnetic coil rests on the person's scalp near the front part of the skull.
- The person is fully awake during the treatment session
- Each treatment takes about an hour
- Usually daily treatment for 1 month then possibly spaced out
- No research data on its use in DSRD or in catatonia, at least 1 case described where it was successful
- Access issues, dependent on insurance





THE UNIVERSITY
OF QUEENSLAND
AUSTRALIA

CREATE CHANGE

Thank you



DrCathyFranklin



Dr Cathy Franklin



DrCathyFranklin



Cathy Franklin

Email: c.franklin1@uq.edu.au
midas@mater.org.au



Down Syndrome Regression Disorder: *IVIg and Immunotherapy Responsiveness*

Jonathan D. Santoro MD

Director of Neuroimmunology
Director of Research, Neurologic Institute
Associate Professor of Neurology and Pediatrics
Children's Hospital Los Angeles
Keck School of Medicine of USC





IVIg: Why start here?

- Initially, patients were only identified as having possible inflammation on imaging and lab studies but no knowledge of the response to immune treatments was known.
- IVIg is a commonly used *immune boosting* medication which is very well tolerated (safe) and easily started/stopped.
- Many different treatments have been used, all with some aspect of success although prediction of who will respond to what therapy best is very difficult.

Early Studies

Immunotherapy in selected patients with Down syndrome disintegrative disorder

KATHLEEN M CARDINALE¹  | ALEXANDRA BOCHARNIKOV¹ | SARAH J HART¹ | JANE ANN BAKER¹ | CHRISTOPHER ECKSTEIN² | JOAN M JASIEŃ¹  | WILLIAM GALLETINE¹ | GORDON WORLEY¹ | PRIYA S KISHNANI¹ | HEATHER VAN MATER¹

- Cardinale et al., reported on four patients with DSRD responding to a variety of immunotherapies in 2019.

Table II: Immunotherapy regimens of each patient

	Patient 1	Patient 2	Patient 3	Patient 4
Time to immunotherapy (mo)	<1	6	6	3
Time to significant improvement (mo)	Immediate	Immediate	2–3	Immediate
Time to peak improvement (mo)	2–3	24	12–15	18
Intravenous steroids	1000mg daily for 3d 1000mg once 1mo later	1000mg daily for 3d	1000mg daily for 3d	
Oral steroids		60mg daily, tapered over 3mo	60mg daily, tapered over unknown duration	
IVIG	2g/kg for 1mo, then 1g/kg monthly for 18mo	2g/kg once	1g/kg every 3mo for 12mo	1g/kg every 6wks (on-going)
Mycophenolate	500mg BID for 3mo	500mg BID	500mg BID	
Rituximab		1000mg every 6mo (on-going)		

Therapies were initiated in descending order. Time to improvement from initiation of therapy is based on physician documentation in the patient record. IVIG, intravenous immunoglobulin; BID, twice a day.

Table 3 Therapeutic responses

Therapy type ^a	Utilization (n (%))	Effectiveness (n (%))			Any neurodiagnostic abnormality vs normal workup		
		All patients (n = 72)	Any neurodiagnostic abnormality (n = 29)	EEG/MRI/CSF normal (n = 43)	X ² value	p value	Odds ratio (95%CI)
Antidepressant	45 (63%)	22 (49%)	4/16 (25%)	18/29 (62%)	5.67	0.02	0.20 (0.05–0.79)
Antipsychotic	52 (72%)	32 (61%)	9/19 (47%)	23/33 (70%)	2.54	0.12	0.39 (0.12–1.26)
Benzodiazepines	63 (87%)	49 (77%)	18/24 (75%)	31/39 (79%)	0.17	0.42	0.77 (0.23–2.59)
ECT	49 (68%)	36 (74%)	6/15 (40%)	30/34 (88%)	12.42	0.01	0.09 (0.02–0.39)
Nutritional therapy	29 (40%)	0 (0%)	0/13 (0%)	0/10 (0%)	0	1.0	n/a
Immunotherapy	43 (59%)	74/120 (62%)	55/74 (74%)	19/46 (41%)	10.04	< 0.001	4.11 (1.88–9.02)
<i>Steroids</i>	39 (54%)	14/39 (36%)	10/24 (42%)	4/15 (27%)	0.90	0.34	1.96 (0.48–7.99)
<i>IVIg</i>	43 (59%)	38/43 (88%)	24/26 (92%)	14/17 (82%)	0.05	0.33	2.57 (0.38–17.31)
<i>Anti-CD20</i>	19 (26%)	9/19 (47%)	9/11 (81%)	0/8 (0%)	9.89	0.01	49.5 (3.84–638.43)
<i>MMF/AZ</i>	19 (26%)	13/19 (68%)	12/13 (92%)	1/6 (17%)	12.17	0.01	60.0 (3.10–1159.84)

AZ Azathioprine, CSF cerebrospinal fluid, EEG electroencephalogram, ECT electroconvulsive therapy, MRI magnetic resonance imaging, MMF mycophenolate mofetil

^a Patients may have received multiple therapeutic interventions creating a higher “n” with regard to the treatment interventions by class

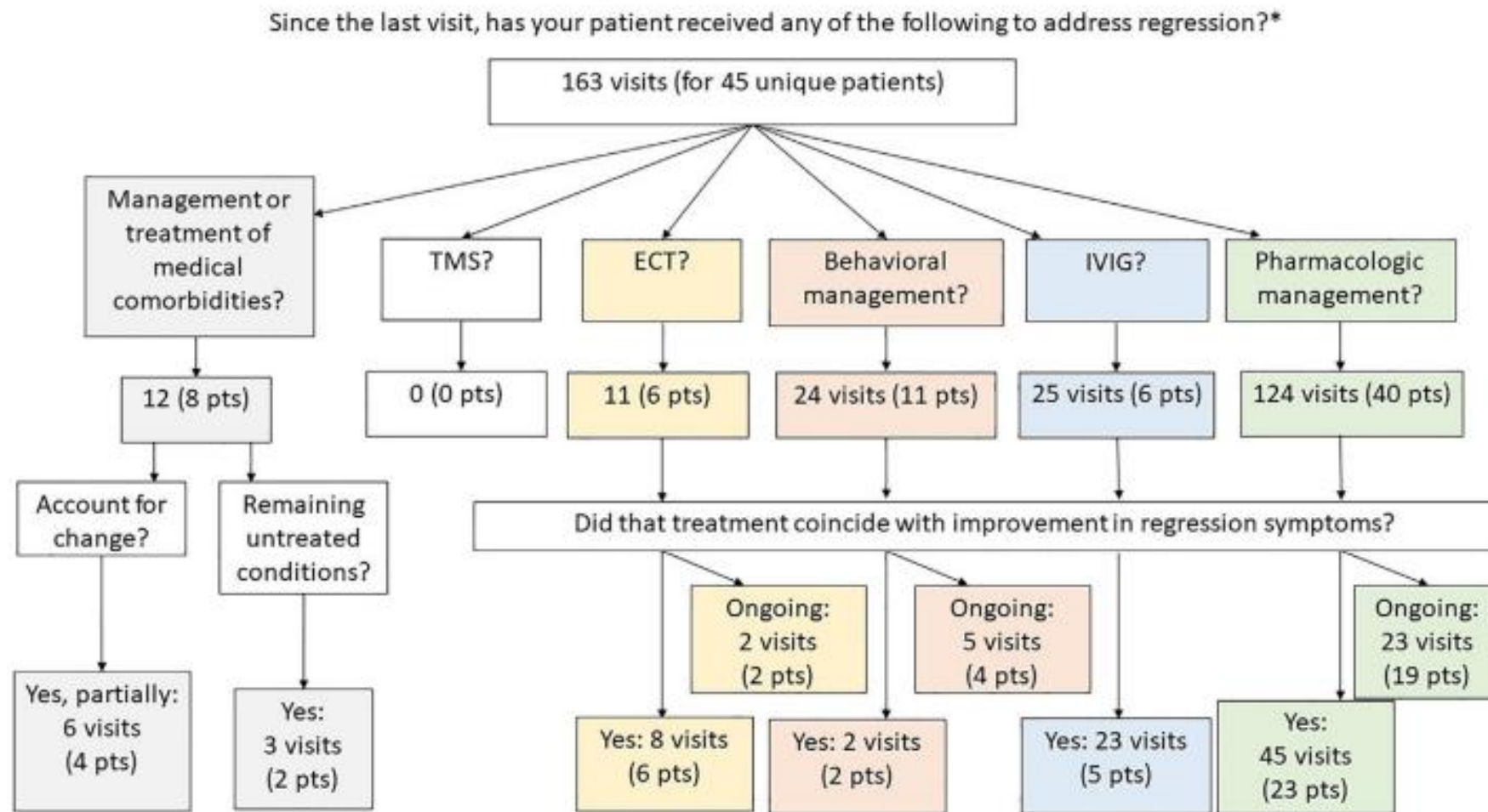
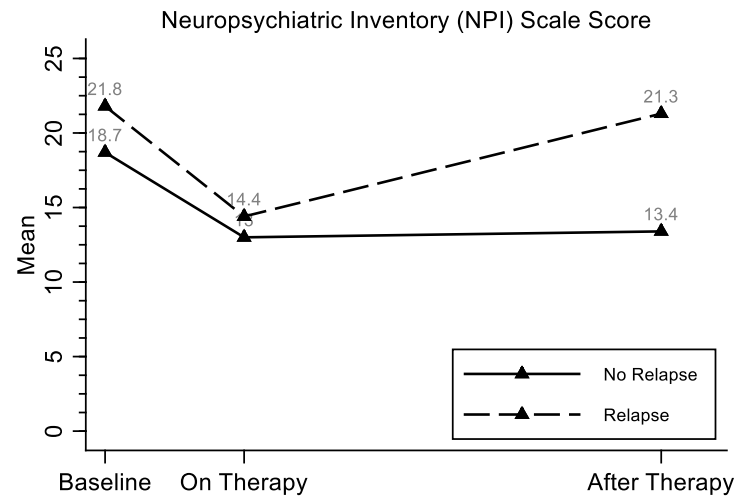
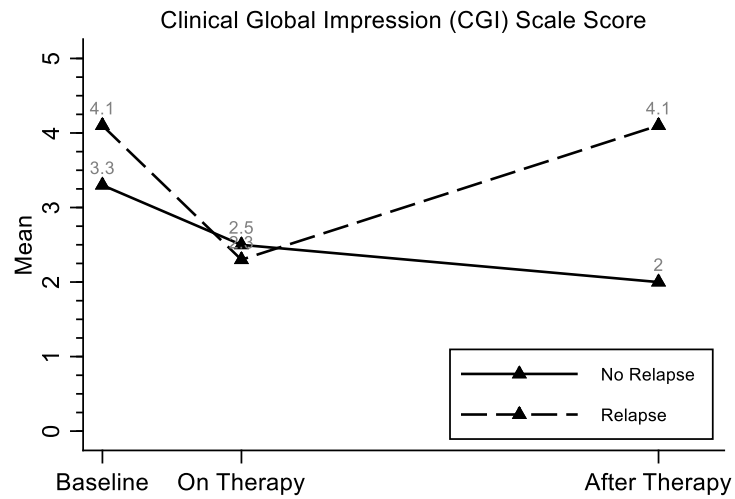
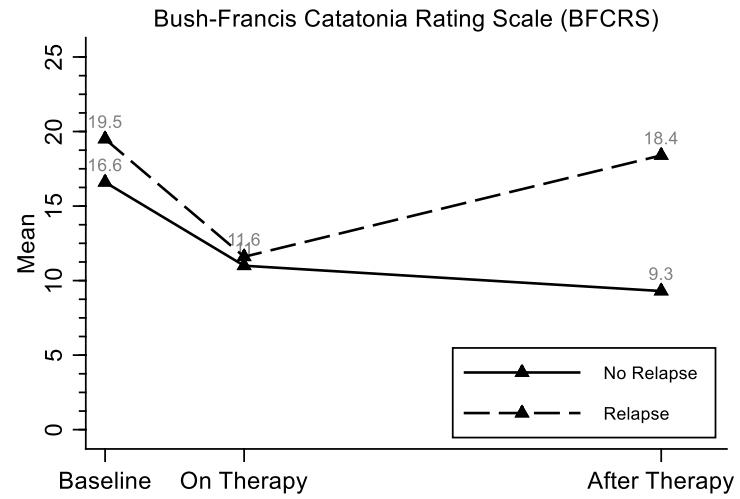
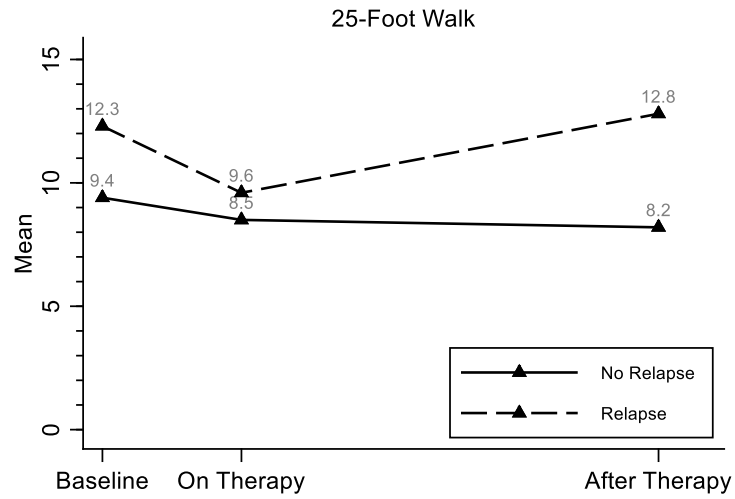


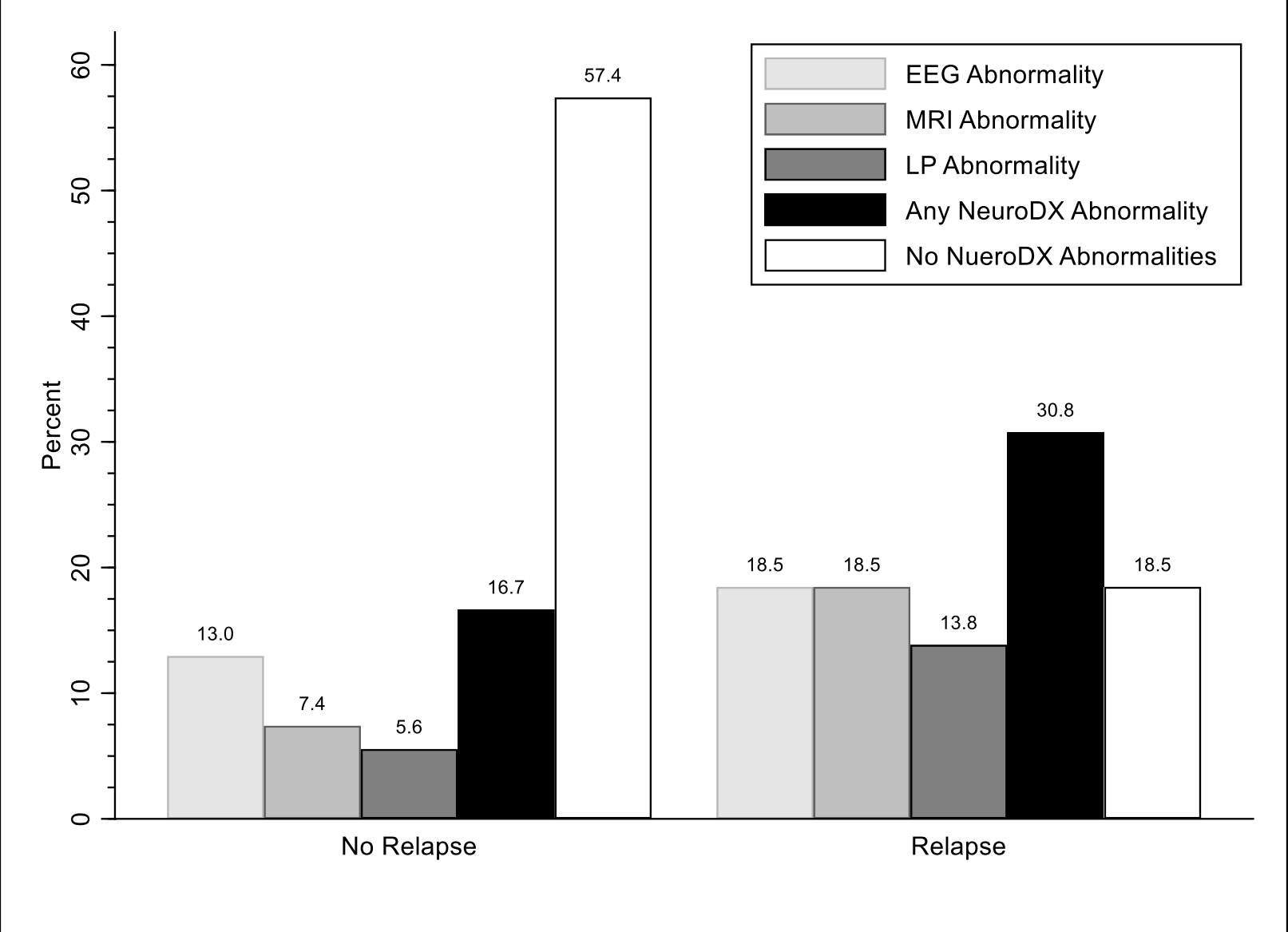
FIGURE 2 Management of patients with unexplained regression in Down syndrome (URDS), and if that management coincided with improvement in symptoms. Patients = pts; *Patients could receive more than one type of management at a single visit.



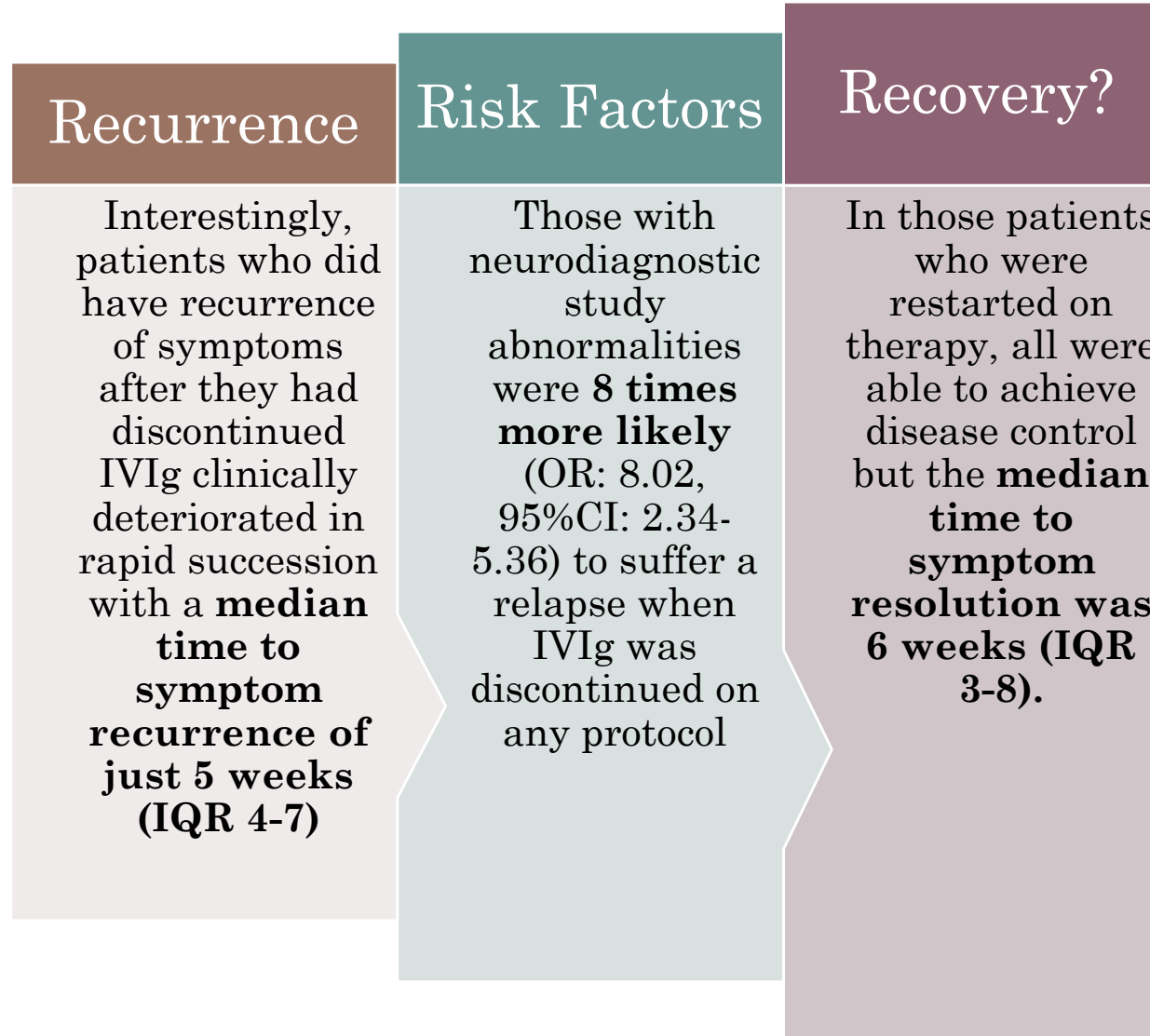
Duration of Treatment?

- Although therapeutic response was noted, nobody knew for certain how long to use IVIg! Given the need for IV placement and its monthly administration, this was a major challenge.
- In 82 patients treated with IVIg for 12 months...
 - 39 (47%) were able to be weaned off therapy without recurrence of symptoms
 - 43 (53%) were not able to be weaned off therapy
 - Recurrence of symptoms occurred at a median of six weeks between infusions (during taper)





Withdrawal Phenomenon



Recurrence

Interestingly, patients who did have recurrence of symptoms after they had discontinued IVIg clinically deteriorated in rapid succession with a **median time to symptom recurrence of just 5 weeks (IQR 4-7)**

Risk Factors

Those with neurodiagnostic study abnormalities were **8 times more likely (OR: 8.02, 95%CI: 2.34-5.36)** to suffer a relapse when IVIg was discontinued on any protocol

Recovery?

In those patients who were restarted on therapy, all were able to achieve disease control but the **median time to symptom resolution was 6 weeks (IQR 3-8).**

Unintended Benefits

- Of individuals treated with IVIg
- In 34 individuals with autoimmune disease reported that there was an improvement in their condition during the start and taper of IVIg
- In 4 patients with a history of rheumatoid arthritis (RA) and joint swelling were improved in all patients



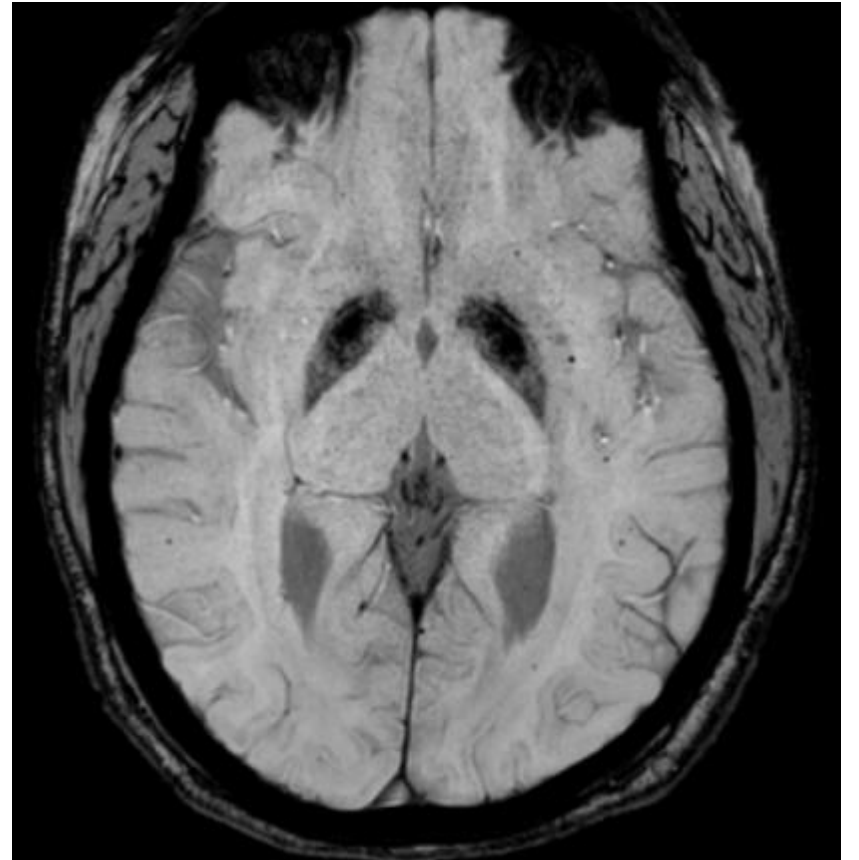
or adverse side effects

(psoriasis, vitiligo, etc.), 88% of patients had a new autoimmune condition associated with the treatment

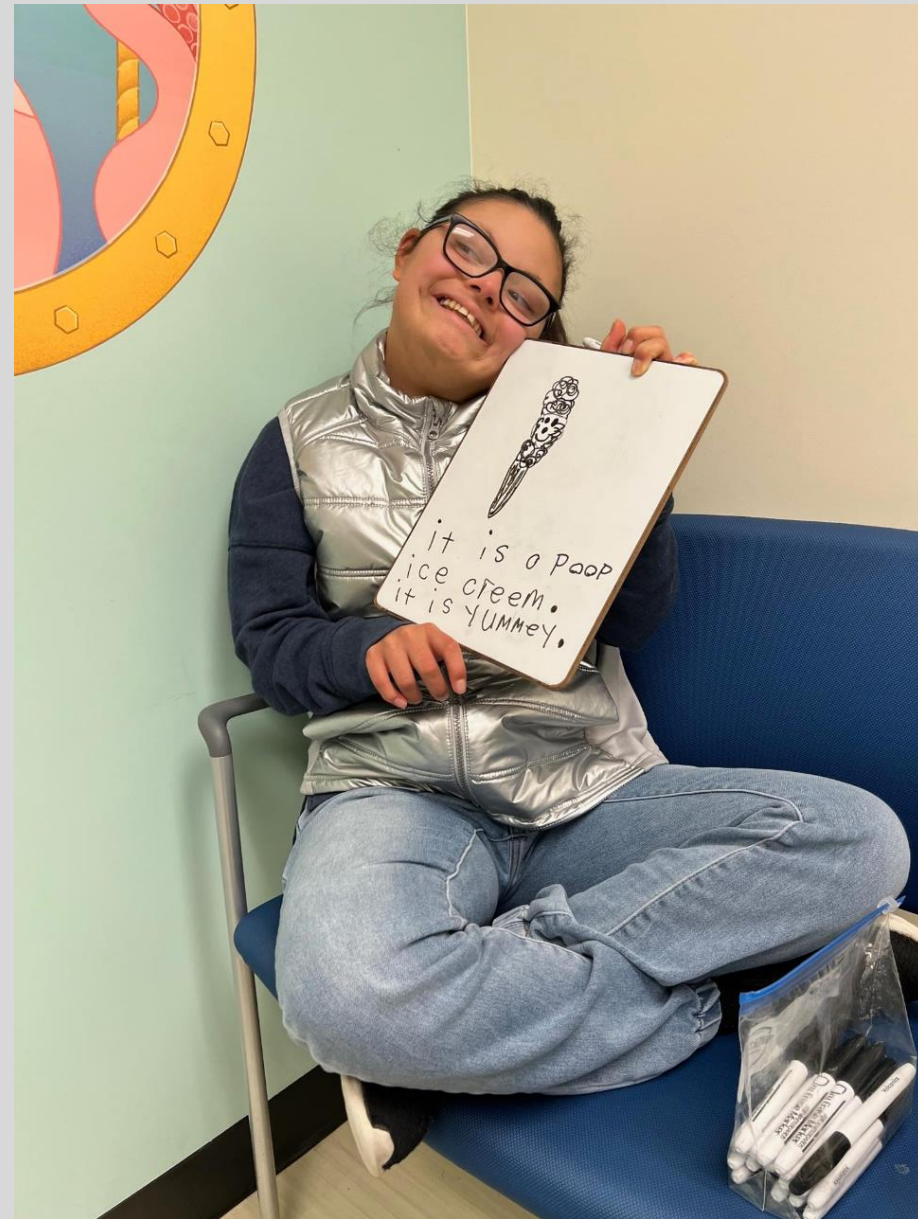
(immunotherapy), pain and joint

Biomarkers of Disease and Response?

- Arriving at the most likely reason for regression in a person with Down syndrome is very important as the therapies that can be offered vary widely on what the explanation is.
- Emerging evidence supports that neuroimaging (MRI) and cerebrospinal fluid (CSF) biomarkers are likely to aid in the prediction of who is most likely to respond to immunotherapy
 - *Latest data identifies this is present in up to 30% of individuals with DSRD compared to 8% in age-matched controls (n= 233). Odds of response to immunotherapy with these findings is up to 9x higher if present on MRI.*



Prognosis



Prognosis

Thank You!



Keck Medicine
of USC



dsresearch@chla.usc.edu

BEHAVIORAL INTERVENTIONS

Lina Patel, PsyD

Linda Crnic Institute for Down Syndrome
Down Syndrome Behavioral Health Collaborative
Aurora, Colorado



PSYCHOLOGICAL APPROACHES TO CHRONIC CATATONIA-LIKE DETERIORATION IN AUTISM SPECTRUM DISORDERS

Amitta Shah* and Lorna Wing†

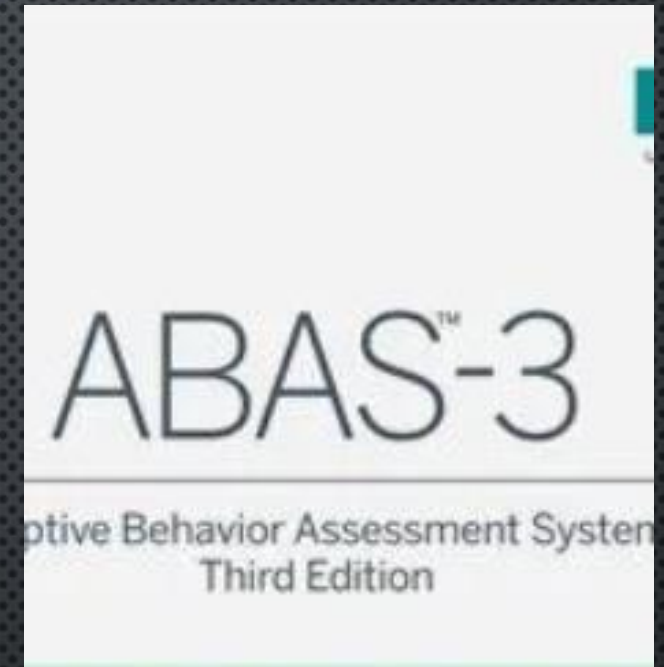
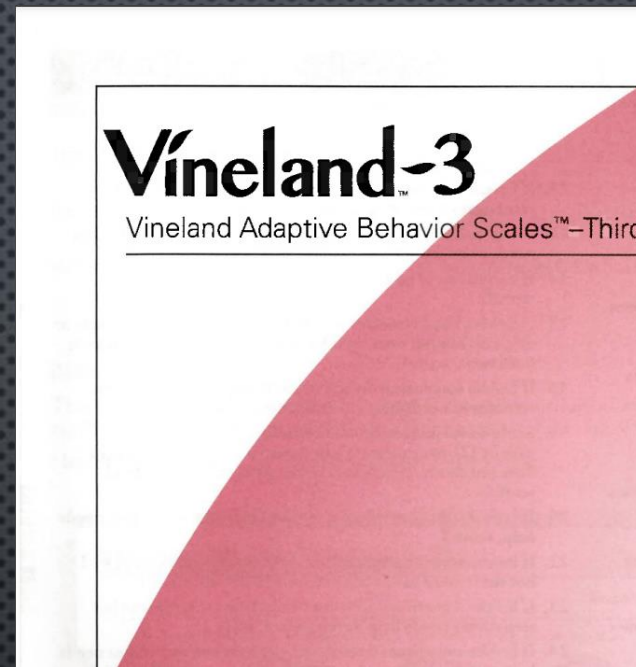
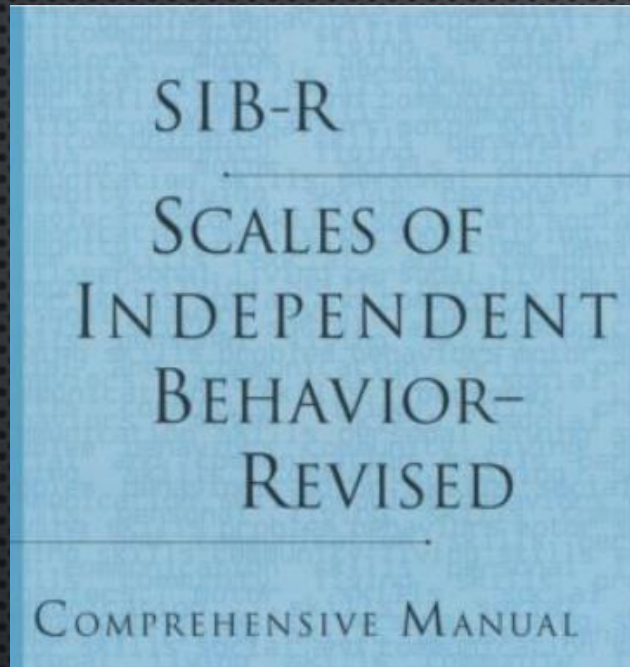
*Leading Edge Psychology, Purley CR8 2EA, United Kingdom

†Centre for Social and Communication Disorders, Bromley, Kent BR2 9HT, United Kingdom

- I. Introduction
- II. Effects of Stress
- III. Effect of Medical Treatments
- IV. Problems with Assessing the Effects of Medical Treatments
- V. Psychological Methods of Intervention

BEHAVIORAL INTERVENTIONS

- COLLECT BASELINE DATA
- INCREASE STRUCTURE — REINTRODUCE VISUAL SUPPORTS, KEEP ROUTINE THE SAME
- IDENTIFY ADDITIONAL COMMUNICATION STRATEGIES
- MINIMIZE TIME ALONE — NO MORE THAN 20 M OF TIME ALONE IN THE ROOM
- COORDINATION OF CARE — INFORM SCHOOL AND COMMUNITY PROVIDERS ABOUT HOW THEY CAN SUPPORT THE INDIVIDUAL
- BEHAVIORAL ACTIVATION — PHYSICAL EXERCISE, TIME WITH FRIENDS, STRUCTURED ACTIVITIES, ABA
- THERAPY — PROCESSING LOSS, TRAUMA, LIFE CHANGES, FRIENDSHIPS, TARGETED INTERVENTION FOR SPECIFIC SYMPTOMS.
- CAREGIVER SUPPORT — RESPITE, THERAPY, CONNECTION TO OTHER FAMILIES













COLLECT BASELINE DATA

















INCREASE STRUCTURE

- REINTRODUCE VISUALS SUPPORTS, IF NEEDED
- KEEP THE ROUTINE THE SAME
- MAINTAIN STABILITY WITHIN SOCIAL INTERACTIONS












Emily's Checklist

-  Eat breakfast
-  Clear the dishes
-  Wipe table/placement
-  Empty dishwasher
-  Get dressed
-  Brush teeth
-  Wash face
-  Brush hair
-  Sunscreen
-  Make bed

What ZONE Am I In?

Blue Zone	Green Zone	Yellow Zone	Red Zone
 Sad  Tired  Sick  Bored	 Calm and Quiet Voice  Ready To Learn  Listening  Quiet Hands	 Silly or Wiggly  Touching Friends  Lie On Floor  Hide/Playing Under Tables	 Mad  Throw  Yelling  Climb

Use these tools to get back and stay in the green zone!

 Drink Some Water	 Count To 10	 Stretch	 Talk To An Adult	 Read A Book	 Go To Safe Zone
 Go For A Walk	 Sensory	 Quiet Break At Desk	 Squeeze Hands	 Listen To Music	

IDENTIFY ADDITIONAL COMMUNICATION STRATEGIES



- CONSIDER COMMUNICATION STRATEGIES THAT PREVIOUSLY WERE SUCCESSFULLY USED
- MAKE SURE THAT THESE STRATEGIES ARE AVAILABLE IN ALL SETTINGS

MINIMIZE ALONE TIME

NO MORE THAN 20 M OF TIME ALONE IN THE ROOM

COORDINATION OF CARE



Inform school and community providers about how they can support the individual



Speak to employers



Facilitate communication between the DSRD treatment team and community providers

BEHAVIORAL ACTIVATION

- PHYSICAL EXERCISE
- TIME WITH FRIENDS
- STRUCTURED ACTIVITIES
- ABA

THERAPY

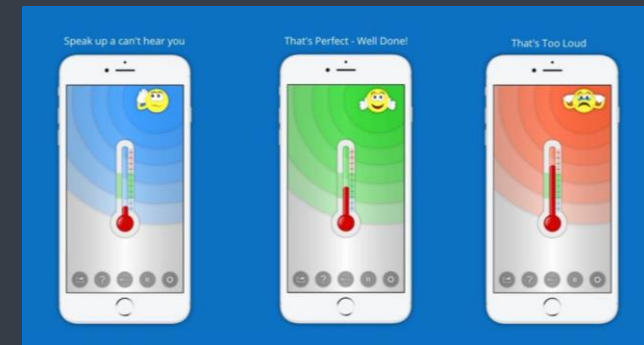
Processing loss

Trauma

Life changes

Friendships

Targeted intervention for specific symptoms



CAREGIVER SUPPORT

- EMOTIONAL SUPPORT: HOPE
- REVIEW OF TREATMENT INTERVENTIONS
- TEAMING
- CAREGIVER STRATEGIES ON PROMPTING



DISCUSSANT

RESOURCES



DS Health Check Tool

DSC2U

- Developed by Prof Brian Skotko and team
- Online, DS-specific health assessment tool that screens for symptoms
- Fee-based, may be covered by insurance
- <https://www.dsc2u.org>

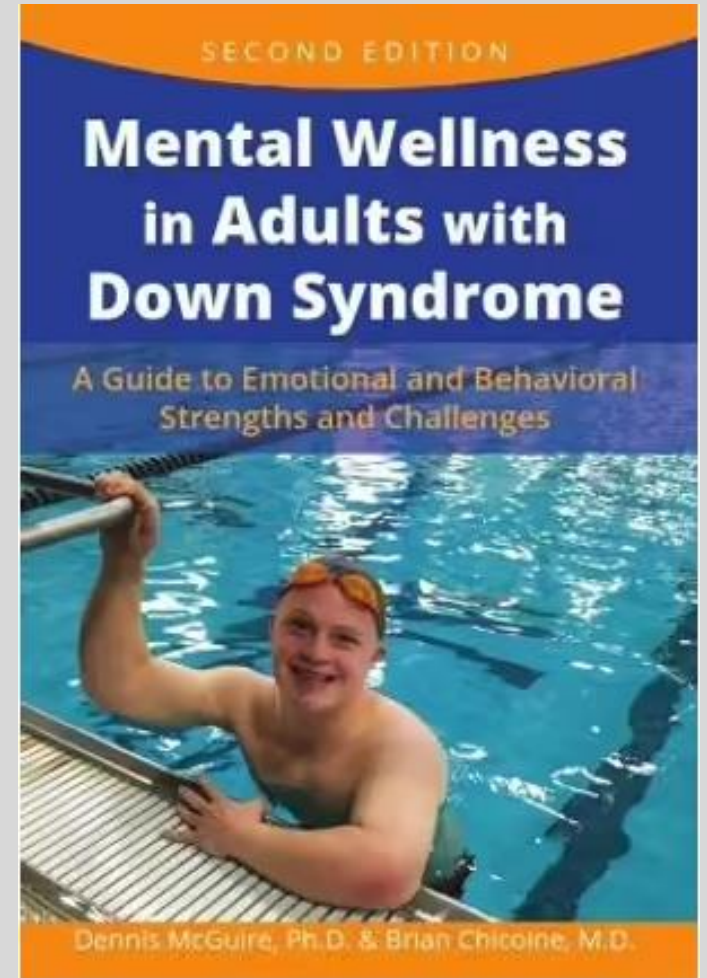


Understanding Mental Wellness in DS

Dennis McGuire and Brian Chicoine's book "Mental Wellness in Adults with Down Syndrome", 2021

NOW available for download at:

<https://adscreources.advocatehealth.com/mental-wellness-in-adults-with-down-syndrome-2nd-edition/>



DSRD Information for Families



REGRESSION & DOWN SYNDROME

CURRENT CONSENSUS UPDATE FOR FAMILIES WHAT IS REGRESSION?

Regression is a term for the loss of previously acquired developmental skills in an individual. This can be in the areas of daily living, language, motor abilities/function, or social interaction. Regression can occur, over weeks to months, or more quickly and time course may help in determining the likely cause of the regression. Regression can be caused by many things and is associated with a marked decline in previously established function. Regression can also be referred to Down syndrome regression disorder (DSRD), Down syndrome disintegrative disorder (DSDD) or unexplained regression in Down syndrome (URDS) and these terms are sometimes used interchangeably.

Download Regression in Persons with Down Syndrome: Current Consensus Update for Families

**Down Syndrome Medical Interest Group-USA
DSMIG-USA is a 501(3)(c) Organization**

- <https://www.dsmig-usa.org/Regression>