

CP STATE CLINICAL CONFERENCE 2025

"I CANNOT GIVE WHAT I DO NOT HAVE" PART ONE: NAVIGATING BURNOUT

Benjamin Margolis, M.D.

Neurologist and Psychiatrist

Art by Alice Farion, Artist Living with Autism



DISCLOSURES/INTRODUCTION

I have no disclosures.

I am board-certified in both neurology and psychiatry, specializing in behavioral healthcare for adults with intellectual and developmental disabilities.

Currently working as an inpatient psychiatrist at Bronx Psychiatric Center, Bronx NY

Member, Special Olympics NY Health Advisory Task Force

Member, OPWDD Health Advisory Task Force

CONTENTS

- ▶ INTRODUCTION - A Talk in Two Parts
- ▶ Why Now - Times are Tough
- ▶ The Wellness Trap - Self-Care as a Burden?
- ▶ Why Now - The Moral Injury Inherent in I/DD Care
- ▶ Clinical Perspective from the Front Line
- ▶ Gifts from the Recovery Community - Idioms for Life
- ▶ A Plea for Kindness in Troubling Times

WHY NOW

- ▶ WHAT WE DO IS REALLY REALLY HARD.
- ▶ It's really hard.
- ▶ People seek relief and solutions from us as clinicians.
- ▶ Sometimes we cannot provide that relief
- ▶ We mean well
- ▶ We manage anger from patients, families, caregivers, staff and face sometimes impossible competing demands

WHY NOW – A TIME RIPE FOR RESENTMENTS



Portrait of a Man Taking Healthcare in a New Direction

WHY NOW – A TIME RIPE FOR RESENTMENTS





NEW YORK
STATE OF
OPPORTUNITY.

**Department
of Health**

KATHY HOCHUL
Governor

JAMES V. McDONALD, M.D., M.P.H.
Commissioner

JOHANNE E. MORNE, M.S.
Executive Deputy Commissioner

DATE: March 26, 2024

TO: Hospitals, Local Health Departments, Laboratories, Emergency Rooms, Family Medicine, Pediatrics, Adolescent Medicine, Internal Medicine, Infectious Disease, Infection Control Practitioners, and Primary Care Providers

FROM: New York State Department of Health, Division of Vaccine Excellence

HEALTH ADVISORY: MEASLES CASE IN NEW YORK STATE

A case of measles has been confirmed in Nassau County, New York in a young unvaccinated child who has not travelled abroad. Given the highly contagious nature of measles, healthcare professionals are urged to take immediate actions to prevent further spread and to manage exposures effectively.

- Providers should be on alert for patients who have febrile rash illness and [symptoms consistent with measles](#) (e.g., cough, coryza, or conjunctivitis) particularly if they have recently traveled abroad, especially to countries with ongoing measles [outbreaks](#). However, recently there have been measles cases without accompanying travel.
- Measles is one of the most contagious infections and individuals are contagious from four days before to four days after rash onset.
- Call ahead to the emergency room if you are sending patients with symptoms of measles to be seen. Medical offices should screen patients for fever and rash and ask about recent travel or exposure to measles at the first point of contact (e.g., during appointment scheduling and at the reception desk).
- Individuals who are exposed to measles without evidence of immunity against measles should be offered post-exposure prophylaxis (PEP). Evidence of immunity is defined as having received two doses of the measles-containing vaccine, positive measles antibody test results, a history of laboratory-confirmed measles, or being born before 1957.
- Providers should assess their current supply of measles post-exposure prophylaxis and consider ordering as needed.
- **Report patients with suspected measles immediately to the [local health department](#) of the patient's residence.** If the residence is in New York City, report persons with suspected measles immediately to the New York City Department of Health and Mental Hygiene at 866-692-3641. **Do not wait for laboratory confirmation to report.**
 - If you have urgent questions regarding measles during evenings, weekends, or holidays, call 866-881-2809.
- Educate patients about vaccines that provide [protection against measles](#). This is especially important [before international travel](#).
- A health advisory issued by the Centers for Disease Control and Prevention can be found at their [website](#).

WHY NOW – A TIME RIPE FOR RESENTMENTS

Congress Weighs Drastic Cuts To Medicaid, Disability Services

by Michelle Diamant | April 28, 2025



As Congress reconvenes this week, lawmakers are expected to put together legislation aimed at cutting taxes and reducing federal spending. (Thinkstock)



The future of the nation’s disability services is on the line, advocates say, as Congress reconvenes to consider legislation that could chop billions from Medicaid.

Learn How Relias’ Learning Management Platform can help your team.

LEARN MORE

RELIAS
relias.com

Find a Job

- ▶ [Executive Director](#)
- ▶ [Vice President of Adult Services](#)
- ▶ [Vocational Coordinator](#)
- ▶ [Nurse Case Manager](#)
- ▶ [Case Manager](#)

VIEW ALL JOBS

POST A JOB

THE BURDEN OF SELF-CARE AND WELLNESS

- ▶ Cognitive Distortion Inherent in Wellness
 - ▶ Placing the Burden of Wellness on the Individual
 - ▶ Institutional and Corporate Wellness Program Limitations
 - ▶ Can Yield Guilt and Shame Surrounding Moral Injury and Burnout

DEFINING OUR TERMS

- ▶ “Burnout is a state of emotional, mental and often physical exhaustion brought on by prolonged or repeated stress. Though it’s most often caused by problems at work, it can also appear in other areas of life, such as parenting, caretaking or romantic relationships.” - Psychology Today

DEFINING OUR TERMS

- ▶ **Moral Injury - Different from Burnout**
 - ▶ “Perpetrating, failing to prevent, bearing witness to, or learning about acts that transgress deeply held moral beliefs or expectations.

DEFINING OUR TERMS

- ▶ **Moral Injury in I/DD Care**
 - ▶ Fear of instances when we cannot protect ourselves
 - ▶ Fear of instances when we cannot protect our patients
 - ▶ Fear of causing potential harm to individuals because we are afraid we have inadequate resources
 - ▶ Taking on roles for which we feel inadequately trained.

DEFINING OUR TERMS

- ▶ **PARTICULARLY AT RISK IN OUR FIELD**
 - ▶ **Long hours**
 - ▶ **High turnover**
 - ▶ **High stakes**
 - ▶ **Limited financial support and remuneration compared to comparable fields**

WHO WE ARE LIKELY TO BE

- ▶ **Family Members and Stakeholders.**
- ▶ **Witnesses to Trauma.**
- ▶ **People who have experienced trauma.**
- ▶ **Individuals with a strong sense of social justice.**

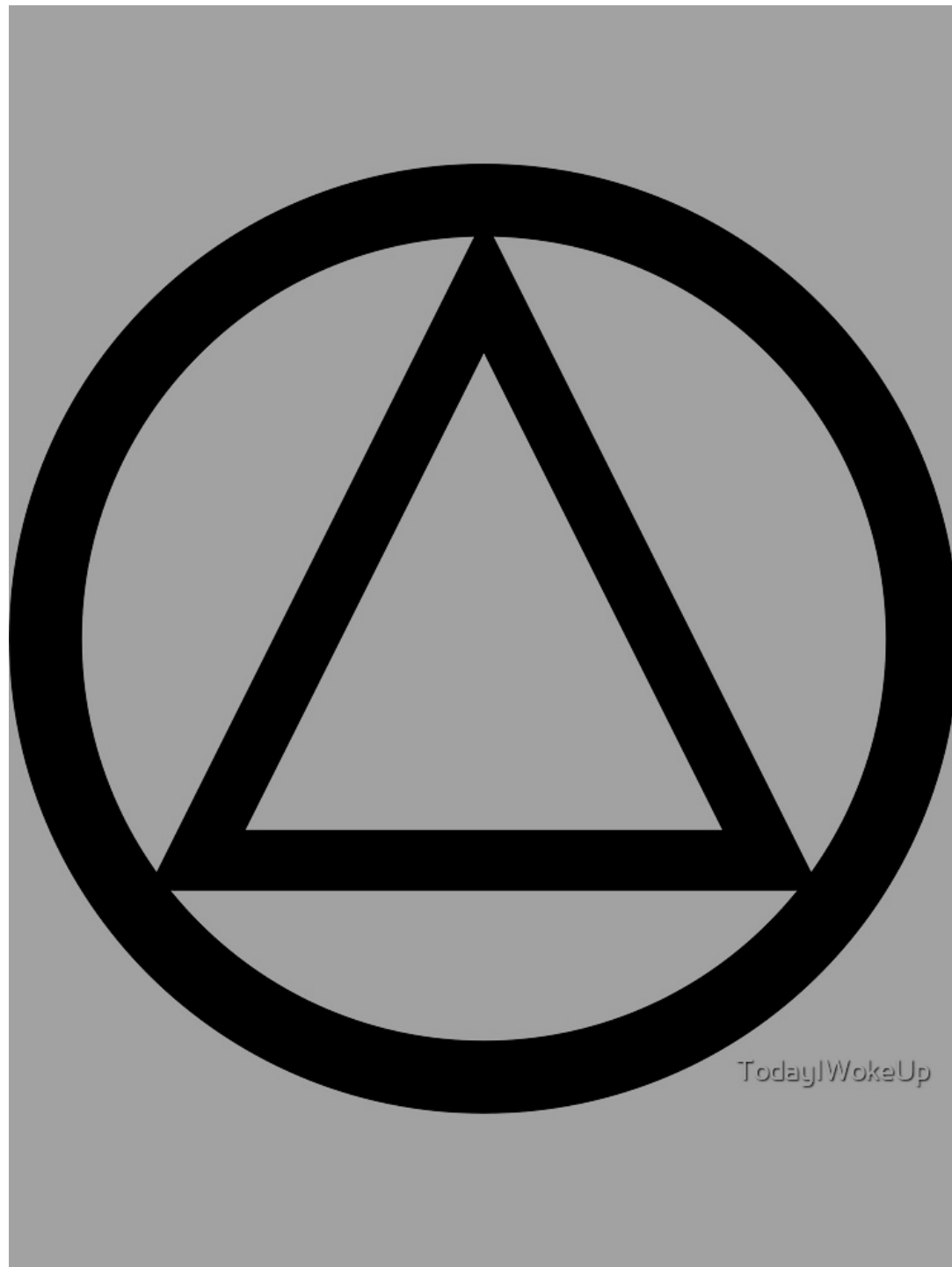
WHO WE ARE LIKELY TO BE

- ▶ **Across the Board Americans See Their Job as a Core Component of a Fulfilling Life**
- ▶ **"We Are What We Do"**
- ▶ **71% of American Adults Identify "Having a Job or Career I Enjoy" as Extremely Important in Having a Fulfilling Life. (Pew Research Center 2023)**

WORDS FROM THE FRONT LINES – OBSERVATIONS OF A CLINICIAN

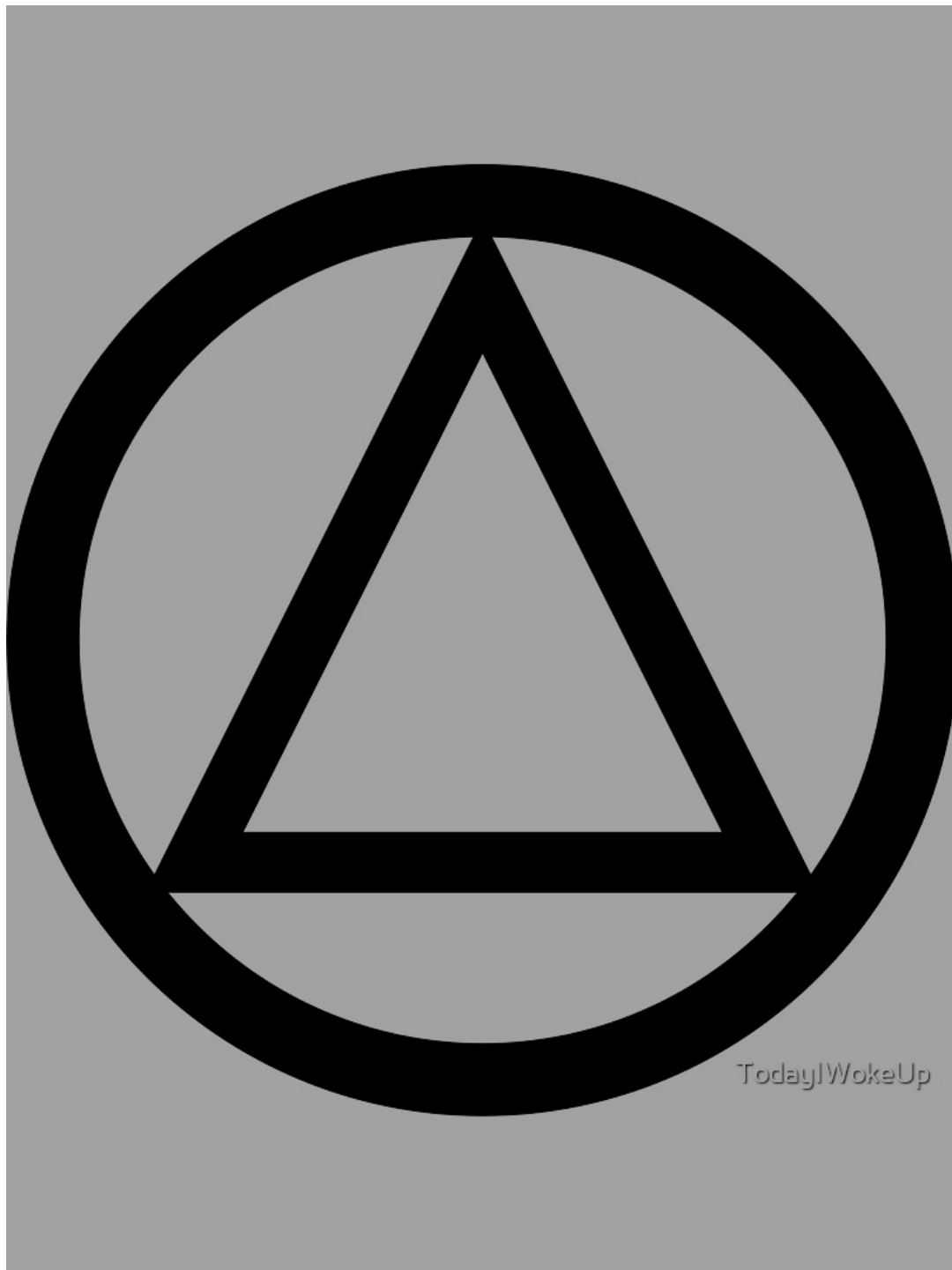
- ▶ **Not claiming to live as an example or to have it hacked.**
- ▶ **Years of working in trauma have pointed toward a spiritual/developmental solution rather than a solely programmatic one.**

WORDS FROM THE FRONT LINES – OBSERVATIONS OF A CLINICIAN



- ▶ **Observations of Those Who Do Best**
- ▶ **A gift from the recovery community**

WORDS FROM THE FRONT LINES – OBSERVATIONS OF A CLINICIAN



- ▶ **Idioms that Drive Kindness, Togetherness and Defeat Cynicism**

WORDS FROM THE FRONT LINES – OBSERVATIONS OF A CLINICIAN

- ▶ **Give up all hope for a better past.**
- ▶ **Accept the things we cannot change, the courage to change what we can, and the wisdom to know the difference.**
- ▶ **As clinicians, we are facing very hard challenges that we DID NOT CAUSE.**
- ▶ **The need for help will be infinite and healthy internal and external boundaries are essential for being able to do this job.**

WORDS FROM THE FRONT LINES – OBSERVATIONS OF A CLINICIAN

- ▶ Healthcare will take whatever you give it - it can take our sleep, our time to eat, our families, our free time, our quality of life and our physical health if we allow it to. We have the ability to know when to stop.
- ▶ **WE CANNOT GIVE WHAT WE DO NOT HAVE**
 - ▶ If we are not able to care for ourselves and each other we **CANNOT CARE FOR OTHERS.**

A PLEA FOR KINDNESS

- ▶ **Reflect kindness anytime we see burnout in ourselves and our colleagues.**
- ▶ **Acknowledge how hard the job we are doing is - we can never do it perfectly.**
- ▶ **Resentments can drive cynicism and burnout - we can insulate ourselves with spiritual and personal connections. The best people in the world are working in this field.**
- ▶ **An offer of respect and gratitude to the field of I/DD care. This is the best of humanity.**
- ▶ **Please accept a celebration and thank you.**

Beadle ES, Walecka A, Sangam AV, Moorhouse J, Winter M, Munro Wild H, Trivedi D, Casarin A. Triggers and factors associated with moral distress and moral injury in health and social care workers: A systematic review of qualitative studies. *PLoS One*. 2024 Jun 27;19(6):e0303013. doi: 10.1371/journal.pone.0303013. PMID: 38935754; PMCID: PMC11210881.

Kathyan Kelly, Haigh Margaret, Mary McCarron, Philip McCallion, Eilish Burke, Andrew David Wormald. Moral distress in carers for people with an intellectual disability who died during the COVID-19 pandemic, a template analysis extending the Barlem and Ramos model of moral distress. *Journal of Applied Research in Intellectual Disabilities* First published: 14 February 2023 <https://doi.org/10.1111/jar.13073>

Wormald A, McGlinchey E, D'Eath M, Leroi I, Lawlor B, McCallion P, McCarron M, O'Sullivan R, Chen Y. Impact of COVID-19 Pandemic on Caregivers of People with an Intellectual Disability, in Comparison to Carers of Those with Other Disabilities and with Mental Health Issues: A Multicountry Study. *Int J Environ Res Public Health*. 2023 Feb 13;20(4):3256. doi: 10.3390/ijerph20043256. PMID: 36833954; PMCID: PMC9965347.

Chua SY, Abd Rahman FN, Ratnasingam S. Problem behaviours and caregiver burden among children with Autism Spectrum Disorder in Kuching, Sarawak. *Front Psychiatry*. 2023 Oct 30;14:1244164. doi: 10.3389/fpsy.2023.1244164. PMID: 37965356; PMCID: PMC10642943.

Pinyopornpanish K, Wajatieng W, Niruttisai N, Buawangpong N, Nantsupawat N, Angkurawaranon C, Jiraporncharoen W. Violence against caregivers of older adults with chronic diseases is associated with caregiver burden and depression: a cross-sectional study. *BMC Geriatr*. 2022 Mar 30;22(1):264. doi: 10.1186/s12877-022-02950-7. PMID: 35354435; PMCID: PMC8969256.

Keesler JM, Troxel J. They Care for Others, But What About Themselves? Understanding Self-Care Among DSPs' and Its Relationship to Professional Quality of Life. *Intellect Dev Disabil*. 2020 Jun 1;58(3):221-240. doi: 10.1352/1934-9556-58.3.221. PMID: 32484886.

Jill M. Crane, Susan M. Haverkamp, Who thrives as a direct support professional? Personal motivation and resilience in direct support, *Research in Developmental Disabilities*, Volume 106, 2020, 103764, ISSN 0891-4222

Gray-Stanley JA, Muramatsu N, Heller T, Hughes S, Johnson TP, Ramirez-Valles J. Work stress and depression among direct support professionals: the role of work support and locus of control. *J Intellect Disabil Res*. 2010 Aug;54(8):749-61. doi: 10.1111/j.1365-2788.2010.01303.x. PMID: 20633203; PMCID: PMC3674855.

Finkelstein A, Bachner YG, Greenberger C, Brooks R, Tenenbaum A. Correlates of burnout among professionals working with people with intellectual and developmental disabilities. *J Intellect Disabil Res*. 2018 Oct;62(10):864-874. doi: 10.1111/jir.12542. Epub 2018 Aug 23. PMID: 30141530.

Lahana E, Papadopoulou K, Roumeliotou O, Tsounis A, Sarafis P, Niakas D. Burnout among nurses working in social welfare centers for the disabled. *BMC Nurs*. 2017 Mar 23;16:15. doi: 10.1186/s12912-017-0209-3. PMID: 28344515; PMCID: PMC5364673.

<https://www.pewresearch.org/social-trends/2023/09/14/what-makes-for-a-fulfilling-life/>

THANK YOU FOR YOUR ATTENTION! QUESTIONS?

BENJAMIN MARGOLIS, M.D.

BENJAMIN.MARGOLIS@GMAIL.COM

CP STATE CLINICAL CONFERENCE 2025

NAVIGATING REFRACTORY CHALLENGES PART TWO: AUTISM RELATED OCD

Benjamin Margolis, M.D.

Neurologist and Psychiatrist

Source: Able Home Healthcare "Competing with the Urge to Pick"



DISCLOSURES/INTRODUCTION

I have no disclosures.

I am board-certified in both neurology and psychiatry, specializing in behavioral healthcare for adults with intellectual and developmental disabilities.

Currently working as an inpatient psychiatrist at Bronx Psychiatric Center, Bronx NY

Member, Special Olympics NY Health Advisory Task Force

Member, OPWDD Health Advisory Task Force

CONTENTS

- ▶ Refractory Behaviors Drive Team Burnout
- ▶ Management Strategies Through Cases
- ▶ 1. Cases of Syndromic Patterns - PWS
- ▶ 2. A Case of Drink Seeking
- ▶ 3. A Case of Deal Making
- ▶ 4. A Case of Phrase Repetition
- ▶ 5. Coprophagia and Very Challenging Behaviors
- ▶ 6. Tools on the Horizon

THE “BEHAVIORAL IRA” AND CASES THAT DRIVE BURNOUT

- ▶ AGAIN - WHAT WE DO IS REALLY REALLY HARD.
- ▶ It's really hard.
- ▶ 10% of my caseload has periodically swelled to take 80% of my time.
- ▶ Refractory Behaviors can Drive Burnout and lead to feelings of Futility - These Cases Are Examples of Hard-Won Successes - Innumerable Failed Trials Are Abbreviated
- ▶ Personal Note

THE “BEHAVIORAL IRA” AND CHALLENGES THAT DRIVE FEELINGS OF FUTILITY

- ▶ Strategies for Managing Seeking Behaviors
 - ▶ Focus Here is on Pharmacotherapy - My Lane
 - ▶ Some Strategies Here are Empiric and Anecdotal - NOT yet supported in literature (as is the nature of this field)
 - ▶ This is NOT to Discount or Minimize Critical NONPHARMACOLOGIC supports

PRADER-WILLI SYNDROME



SOURCE:

Rick Guidotti

POSITIVE EXPOSURE

Note - this is a wonderful individual with living with PWS - not our patient, a different wonderful individual living with PWS.

SYNDROMIC CHALLENGES

- ▶ Prader Willi Brief Review
 - ▶ Three Major Genetic Causes
 - ▶ Paternally Inherited Chromosome 15 Deletion - 75%
 - ▶ Maternal Uniparental Disomy (two Chromosome 15 copies from mother - 25%)
 - ▶ 1 in 10,000 to 1 in 30,000 People Worldwide

SYNDROMIC CHALLENGES

▶ PEDRO

- ▶ Pedro is a 28 y/o man living with Prader-Willi Syndrome in a home dedicated to the care of individuals with PWS
- ▶ He is of Central American descent and he is an only child. His parents are divorced, and his mother is his primary advocate. He loves horror movies and we are all gifted with nicknames from his favorite horror classics.

SYNDROMIC CHALLENGES

▶ PEDRO

- ▶ He is tall, thin and has hypogonadism. He has chronic weakness.
- ▶ He struggles with pica and refractory hunger, pathognomonic of PWS.
- ▶ He struggles with skin picking when anxious and frequently pulls off fingers and toenails.
- ▶ Tantrum behaviors and disrobing emerge when he is frustrated.
- ▶ His challenges have emerged when in program and have stopped him from participating.

SYNDROMIC CHALLENGES

▶ PEDRO

- ▶ He has a history of significant trauma and his family reports that he was physically abused by a prior caregiver. He declines to discuss this when queried.
- ▶ He also has a history of allegations which have been shown to be false.

SYNDROMIC CHALLENGES

▶ PEDRO

- ▶ Brief note on trauma and veracity - "People can have both tics and fleas - or as many diseases as they damn well please."
- ▶ Allegations drove frequent staff turnover, burnout, resentments.
- ▶ Maladaptive Behaviors were imitated by others in the home.

SYNDROMIC CHALLENGES

- ▶ PEDRO

- ▶ FIRST LINE - SSRI - BUT WHICH SSRI?

SYNDROMIC CHALLENGES

- ▶ PEDRO
 - ▶ CONSIDERATIONS OF SIDE EFFECT PROFILE
 - ▶ CONSIDERATION OF INTERACTIONS
 - ▶ fluoxetine

SYNDROMIC CHALLENGES

- ▶ PEDRO

- ▶ SECOND LINE - SGA (Second Generation Antipsychotic)

SYNDROMIC CHALLENGES

▶ PEDRO

- ▶ Which Second Generation Antipsychotic?
- ▶ FDA Approved Options for Aggression in Autism -
 - ▶ risperidone
 - ▶ aripiprazole

SYNDROMIC CHALLENGES

- ▶ PEDRO
 - ▶ Side Effect Profile Consideration
 - ▶ Appetite Appetite Appetite
 - ▶ Gastric Motility Concerns

SYNDROMIC CHALLENGES

- ▶ PEDRO
 - ▶ Managing Skin Picking
 - ▶ Third Line Options Needed
 - ▶ **NALTREXONE OFF LABEL**
 - ▶ **Extinction Burst Avoidance**

SYNDROMIC CHALLENGES

- ▶ PEDRO

- ▶ Pedro's Doing Great.

- ▶ He Feels I've Earned My Horror Movie Nickname:

- ▶ "Dr. Margolis"

DRINK SEEKING



SOURCE: Alamy Stock Photos

REFRACTORY DRINK/COFFEE SEEKING

▶ KYLE

- ▶ 35 y/o Man from New England. He has moderate intellectual disability, autism, and epilepsy.
- ▶ He does not use words to communicate.
- ▶ He LOVES coffee.
- ▶ He will run into a room and attempt to drink anyone else's coffee.

REFRACTORY DRINK/COFFEE SEEKING

▶ KYLE

- ▶ Management with Informal Alarm System (System at Day Program)
- ▶ Risks in the Community (Story of the Store)
- ▶ Risks of Hyponatremia (Health)
- ▶ Other concerns for Water Play / Fixations (Building)

REFRACTORY DRINK/COFFEE SEEKING

- ▶ KYLE

- ▶ First Line? SSRI

- ▶ Hyponatremia Considerations

- ▶ Interaction Profile

REFRACTORY DRINK/COFFEE SEEKING

- ▶ KYLE

- ▶ Second Line? SGA or FGA

- ▶ Interaction Profile Considerations

- ▶ Trials of olanzapine, chlorpromazine, aripiprazole not effective.

- ▶ Haloperidol not effective

REFRACTORY DRINK/COFFEE SEEKING

- ▶ KYLE

- ▶ OFF-LABEL COMBINATION THERAPY

- ▶ SSRI/CBZ

- ▶ Fluoxetine and Carbamazepine

REFRACTORY DRINK/COFFEE SEEKING

▶ KYLE

- ▶ Carbamazepine Utilized for his Epilepsy
- ▶ Levels between 10 and 11 in conjunction with fluoxetine controlled OCD Behaviors
- ▶ Limited Evidence - Anecdotal Support
- ▶ Risks - Interactions
 - ▶ Hyponatremia, Granulocytopenia

REFRACTORY DRINK/COFFEE SEEKING

- ▶ KYLE - NOT JUST AN N OF ONE
 - ▶ Further Study is REQUESTED!!!

REFRACTORY DRINK/COFFEE SEEKING

- ▶ KYLE - NOT JUST AN N OF ONE
 - ▶ Further Study is REQUESTED!!!

DEAL MAKING – AND DEALMAKING – AND DEALMAKING



DEALMAKING AND DEALMAKING AND DEALMAKING

▶ Devon

- ▶ 37 y/o Man from New England with mild intellectual disability and OCD, along with autism. He has a love of gangster rap.
- ▶ He has no family involvement in his life - he lives in an IRA with 6 housemates.
- ▶ He negotiates EVERY aspect of his life and ADLs. He cannot do anything without dealmaking.

DEALMAKING AND DEALMAKING AND DEALMAKING

▶ Devon

- ▶ When his staff will agree to the terms of an agreement, he will continue to harp on it working himself into a rage.
- ▶ "The box is not checked."
- ▶ He has progressed to serious self-injury when ramped up dealmaking. He prolapsed his lower intestine with a fork when agitated and required a large resection.

DEALMAKING AND DEALMAKING AND DEALMAKING

- ▶ Devon
 - ▶ Numerous SSRI trials failed.
 - ▶ Numerous SGA trials failed.
 - ▶ Cheeking was an issue as part of dealmaking.
 - ▶ LONG ACTING INJECTABLE ANTIPSYCHOTICS ARE STILL AN OPTION IN IRAS.

DEALMAKING AND DEALMAKING AND DEALMAKING

▶ Devon

- ▶ Some incomplete but some response to INJECTABLE risperidone.
- ▶ Adherence to his regimen became easier with Consta.
- ▶ OUR OLD FRIENDS TRICYCLICS REMAIN EFFECTIVE

DEALMAKING AND DEALMAKING AND DEALMAKING

- ▶ Devon
 - ▶ Clomipramine for OCD
 - ▶ Clinical considerations
 - ▶ Cardiac Considerations
 - ▶ Epilepsy Considerations.

**I NEED YOU TO REPEAT I JUST NEED YOU TO REPEAT
CAN YOU JUST WRITE THIS DOWN FOR ME....**

Baloney	Flummery	Shuck	Plimt	Shipes
Bambosh	Fribble	Skittles	Keft	Miltive
Bilge	Fustian	Slipslop	Plob	Challer
Blague	Galbanum	Spinach	Bript	Zike
Blarney	Galimatias	Squit	Whib	Zave
Bletherskate	Gammon	Rannygazoo	Queck	Diffed
Brimborion	Gibberish	Razzmatazz	Drix	Shise
Bugaboo	Grimgribber	Rhubarb	Flig	Shrave
Buncombe	Haver	Riddle-me-ree	Swaft	Gisted
Bunk	Hogwash	Rottack	Frest	Woseness
Bushwa	Hooey	Schmegeggy	Splon	Yestive
Cack	Humbug	Taradiddle	Stup	Thofting
Claptrap	Jabberwock	Tarradiddle	Bletch	Spanes
Clatfart	Kelter	Tootle	Whix	Skider
Codswallop	Kidology	Tosh	Vleck	Whuffy
Effutiation	Macaroni	Trumpery	Blonger	Tades

OBSESSIVE PHRASE REPETITION

▶ Steven

- ▶ 48 y/o Man from the Hudson Valley, NY. He has a family who is supportive but who are unable to manage his increasing demands.
- ▶ He has mild intellectual disability, tall stature, and a lifelong history of disinhibition and SIBs when frustrated.
- ▶ He carries diagnoses of OCD and bipolar disorder.

OBSESSIVE PHRASE REPETITION

▶ Steven

- ▶ He obsessively goes through lists, similar to the prior patient. He will ramp up requesting that staff write things down for him, read things to him or answer the same questions innumerable times until they feel “juts right.”
- ▶ Periodically he will stop sleeping, get louder, stop eating and for several weeks his behaviors will get worse requiring hospitalization on multiple occasions.

OBSESSIVE PHRASE REPETITION

- ▶ Steven
 - ▶ He has severely injured several staff members.
 - ▶ He has blinded himself in one eye from an SIB
 - ▶ He has fractured multiple bones during SIBs.
 - ▶ He has not responded to any neuroleptic and serotonergic agents have driven manias.

OBSESSIVE PHRASE REPETITION

▶ Steven


- ▶ His behaviors have lasted for years and have worsened independent of any mediation trials.
- ▶ He has grown worse and more refractory over time.
- ▶ Staff is burning out due to feelings of futility.

VERBIGATION – AGITATION – CATATONIA

▶ Steven

- ▶ He is not responding to medication as he has become catatonic and has been struggling with agitated catatonia, often under-recognized in autism.
- ▶ He requires ECT.

CATATONIA IN AUTISM CAN APPEAR AS OR ACCOMPANY OBSESSIVE BEHAVIORS



[Patient Care](#)
[Education](#)
[Research](#)
[Community](#)
[About URM](#)
[Referring Physicians](#)
[Get Care Now](#)
[MyChart](#)

Department of Psychiatry: Bush-Francis Catatonia Rating Scale Assessment Resources


[About Us](#)
[Our Divisions](#)
[Patient Care](#)
[Education](#)
[Research](#)
[Community](#)
[Our Faculty](#)
[News & Events](#)
[Emergency Services](#)

[URMC](#) / [Psychiatry](#) / [Our Divisions](#) / [Collaborative Care and Wellness](#) / Bush-Francis Catatonia Rating Scale

[Make a Gift](#)


Bush-Francis Catatonia Rating Scale Assessment Resources

[Joshua Wortzel](#) and [Mark Oldham](#) have developed the following educational resources on how to assess for catatonia using the Bush-Francis Catatonia Rating Scale (BFCRS) in collaboration with [Andrew Francis](#).

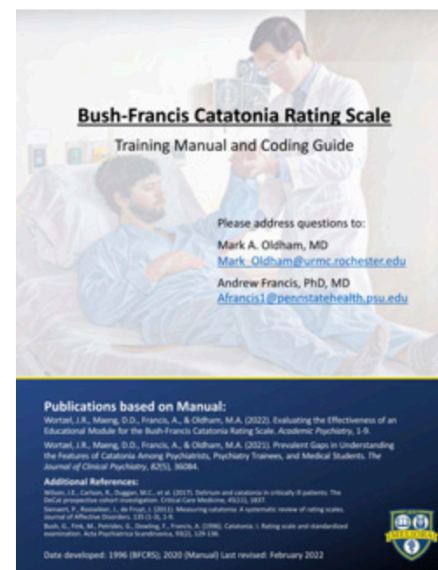
- [BFCRS Training Manual & Coding Guide](#)


Describes how to use the BFCRS and explains each item in detail.
- [Educational modules on using the BFCRS](#)

Standardized patient videos and test questions with explanations.
- [Videos on scoring individual BFCRS items](#)

These can also be accessed from the [PDF version of the BFCRS](#) .
- [BFCRS calculator with descriptions & videos \(mobile optimized\)](#)

Developed in collaboration with [Patrick Ying](#).



<https://www.urmc.rochester.edu/psychiatry/divisions/collaborative-care-and-wellness/bush-francis-catatonia-rating-scale>

EXTREMES OF BEHAVIOR – REFRACTORY SEEKING – 3RD LINE AGENTS



SOURCE:

<https://preventawear.com/products/kylapparel-sensory-friendly-anti-strip-bodysuit>

Note - this is a wonderful individual modeling a nonpharmacologic intervention for behavioral challenges - not our patient

COPROPHAGIA AND PICA

▶ Irene

- ▶ 67 y/o woman with refractory pica that has worsened with time. She has profound intellectual disability, she has autism and she does not use words. She does not follow verbal commands but recognizes body language and some signs.
- ▶ She loves nearly all food except carrots, which she finds repulsive.
- ▶ She has digging behaviors, coprophagia and seeking.
- ▶ Nonpharmacologic options are limited in response.
- ▶ One-piece suit, locked cabinets have been partially effective.

COPROPHAGIA AND PICA

▶ Irene

- ▶ 31 y/o woman with refractory pica that has worsened with time. She has profound intellectual disability, she has autism and she does not use words. She does not follow verbal commands but recognizes body language and some signs.
- ▶ She loves nearly all food except carrots, which she finds repulsive.
- ▶ She has digging behaviors, coprophagia and seeking.
- ▶ Nonpharmacologic options are limited in response.
- ▶ One-piece suit, locked cabinets have been partially effective.

COPROPHAGIA AND PICA

▶ Irene

- ▶ Her behaviors are extreme enough to require full-time 1:1 and sometimes 2:1 staffing,
- ▶ She has trialed SSRIs, TCAs, 1st and 2nd generation antipsychotics and there has been limited response.
- ▶ Combination therapies have yielded limited response.
- ▶ Her family feels frustrated with her ongoing limited response, and are frequently expressing their frustration to her care team.

COPROPHAGIA AND PICA

▶ Irene

- ▶ Her support staff are feeling under appreciated, angry and dismissed.
- ▶ Her caregivers are struggling with feelings of futility.
- ▶ Her family feel that the system have failed them and are looking for ways to take out their anger with her behaviors - her guardian has threatened legal action against her care team as her activities are limited and as she has injured herself.

COPROPHAGIA AND PICA

- ▶ Irene

- ▶ Her family doesn't know where to turn for help aside from the Justice Center.

COPROPHAGIA AND PICA

▶ Irene

- ▶ Clinical meetings with her psychiatric and behavioral care team provide opportunities for calm and collected engagement.
- ▶ Communication can be facilitated in a clinical setting - we need resources to support long visits.
- ▶ With a 90 minute visit everyone's' concerns can be addressed and the team can be heard.

COPROPHAGIA AND PICA

▶ Irene

- ▶ These visits are not a panacea - they are places where grievances can be transformed into communication.
- ▶ Pharmacologic options can be discussed during these visits as well.

COPROPHAGIA AND PICA

- ▶ A happy story for Irene
 - ▶ RILUZOLE 50mg PO BID - not a panacea, but she was able to once again participate in community activities.
 - ▶ Fourth Line Agents can Sometimes help when other options have failed.

- Butler MG, Miller JL, Forster JL. Prader-Willi Syndrome - Clinical Genetics, Diagnosis and Treatment Approaches: An Update. *Curr Pediatr Rev*. 2019;15(4):207-244. doi: 10.2174/1573396315666190716120925. PMID: 31333129; PMCID: PMC7040524.
- Bull LE, Oliver C, Woodcock KA. Skin Picking in People with Prader-Willi Syndrome: Phenomenology and Management. *J Autism Dev Disord*. 2021 Jan;51(1):286-297. doi: 10.1007/s10803-020-04504-5. PMID: 32495267.
- Varghese K, Yan X, Cao F. Low-Dose Naltrexone for Excoriation Disorder. *Cureus*. 2024 Mar 1;16(3):e55336. doi: 10.7759/cureus.55336. PMID: 38559544; PMCID: PMC10981904.
- Benjamin E, Buot-Smith T. Naltrexone and fluoxetine in Prader-Willi syndrome. *J Am Acad Child Adolesc Psychiatry*. 1993 Jul;32(4):870-3. doi: 10.1097/00004583-199307000-00025. PMID: 8340312.
- Del Casale A, Sorice S, Padovano A, Simmaco M, Ferracuti S, Lamis DA, Rapinesi C, Sani G, Girardi P, Kotzalidis GD, Pompili M. Psychopharmacological Treatment of Obsessive-Compulsive Disorder (OCD). *Curr Neuropharmacol*. 2019;17(8):710-736. doi: 10.2174/1570159X16666180813155017. PMID: 30101713; PMCID: PMC7059159.
- Koopowitz LF, Berk M. Response of obsessive compulsive disorder to carbamazepine in two patients with comorbid epilepsy. *Ann Clin Psychiatry*. 1997 Sep;9(3):171-3. doi: 10.1023/a:1026282008726. PMID: 9339883.
- Joffe RT, Swinson RP. Carbamazepine in obsessive-compulsive disorder. *Biol Psychiatry*. 1987 Sep;22(9):1169-71. doi: 10.1016/0006-3223(87)90061-8. PMID: 3651536.
- Moore S, Amatya DN, Chu MM, Besterman AD. Catatonia in autism and other neurodevelopmental disabilities: a state-of-the-art review. *Npj Ment Health Res*. 2022 Sep 14;1(1):12. doi: 10.1038/s44184-022-00012-9. PMID: 38609506; PMCID: PMC10955936.
- Pittenger C. Glutamatergic agents for OCD and related disorders. *Curr Treat Options Psychiatry*. 2015 Sep;2(3):271-283. doi: 10.1007/s40501-015-0051-8. PMID: 26301176; PMCID: PMC4540409.

THANK YOU FOR YOUR ATTENTION! QUESTIONS?

BENJAMIN MARGOLIS, M.D.

BENJAMIN.MARGOLIS@GMAIL.COM