CP STATE VIRTUAL CONFERENCE 2024

CO-OCCURING CONDITIONS AMONG INDIVIDUALS WITH I/DD AND PSYCHOTROPIC MEDICATIONS

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Access: Supports for Living

Art by Tristan

Access Gallery, Denver CO (accessgallery.org)

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.

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CONTENTS – NOTE CME CONSIDERATIONS ARE INDICATED AND IN RED

- I. REVIEWING WHERE WE ARE - Prescribing, Diagnoses and Public Health in I/DD.
- II. FUNDAMENTALS - MANAGING BEHAVIOR vs. PSYCHIATRIC CARE
- III: FUNDAMENTALS - DIAGNOSTIC OVERSHADOWING - OUR COLLECTIVE CHALLENGE
- IV. AN INTERDISCIPLINARY TEMPLATE FOR CARE ACROSS THE BOARD
- V: A SMATTERING OF SYNDROMES
- VI: THE TASKS AHEAD - CHALLENGES FOR OUR FIELD TO SOLVE TOGETHER

"WHEN ALL YOU HAVE IS A HAMMER, THEN EVERYTHING LOOKS LIKE A NAIL"

- I: Where We Are - Prescribing in I/DD
  - Challenging Behaviors are very common among persons with I/DD
  - Challenging Behaviors do NOT always represent psychiatric disease - BUT SOMETIMES THEY DO!!!!
  - The lay of the land at this time:

I: WHERE WE ARE – PRESCRIBING PATTERNS IN I/DD

- 2018 Ontario Study - 39.2% of all adults with I/DD prescribed antipsychotics, 56.4% in group homes.
  28.9% of all those prescribed antipsychotics had NO psychiatric diagnosis. (Lunsky et al Can J Psych 2018)
- 2015 UK Primary Care Study - 49% of 33,000 adults with I/DD had record of being prescribed antipsychotics for challenging behavior. (Sheehan et al BMJ 2015)
- 2013 New York State Study - Among 4069 adults with I/DD, 58% received one or more psychotropics, 45% treated with antipsychotics. 50% of all psychotropic prescriptions were for psychiatric diagnoses (Tsiouris et al J Autism Dev Disord 2013)

I: WHERE WE ARE – PRESCRIBING PATTERNS IN I/DD

- Rule of Thumb - About half of the patients with I/DD we see are treated with psychotropic medications.
- Rule of Thumb - About half of those have been formally diagnosed with psychiatric illness.
- Attempts in our field to change in this pattern have not yielded significant changes.
- Glasgow Example, 10 year prospective cohort - Most people aren't weaned from medication once started, and medications tend to continue to be added when problematic behaviors continue (Henderson et Al, BMJ 2020).

II: MANAGING BEHAVIORS WHICH CAN SOMETIMES BE EXTREME

- What does this mean? Are doctors prescribing inappropriately?
- IN SOME CASES YES:
  - AADMD and NCIDM is addressing with EDUCATION
  - Cultural Competency Can Address
  - Diagnostic Overshadowing, as covered later

II: MANAGING BEHAVIORS WHICH CAN SOMETIMES BE EXTREME

- What does this mean? Are doctors prescribing inappropriately?
- IN SOME CASES NO:
  - EMRs and LIMITED DATA COLLECTION IMPAIRS ABILITY TO ACCURATELY TRACK DIAGNOSES
  - We are primarily working in off-label territory and diagnostic accuracy is more challenging in the setting of medical complexity.

II: WORKING OFF-LABEL AND IN THE SETTING OF AMBIGUITY

- For Autism-related aggression, we are limited to TWO FDA APPROVED AGENTS (NOTE THIS FOR CME):
- **Risperidone approved in 2005**
- **Aripiprazole approved in 2009**
- Everything else is off-label, however many mood, anxiety and sometimes thought disorders are CO-OCCURING AND HAVE ON-LABEL TREATMENTS. (LeClerc, 2015)

III: DIAGNOSTIC OVERSHADOWING AND I/DD

- Before we discuss ON-LABEL TREATMENTS for co-occuring diagnoses, we'll discuss pitfalls and risks for treatment.

- WE CAN ALL GET FOOLED EVEN THOUGH WE'RE CAREFUL - reassessment is always necessary

- DIAGNOSTIC OVERSHADOWING DEFINITION REVIEW

III: DIAGNOSTIC OVERSHADOWING – SOMEHOW STILL A CONSTANT RISK

- This audience is likely to know this - update from 2021
- IS A BEHAVIOR OR PSYCHIATRIC SYMPTOM AN EXPRESSION OF AN ALTERNATIVE PROBLEM?
- We can never be complacent - reassessment is always needed! DIFFERENT DISTRESS CAN PRESENT WITH THE IDENTICAL BEHAVIORS in an individual.
- Busy clinicians with limited cultural competency are at highest risk - know the other docs caring for an individual!

III: DIAGNOSTIC OVERSHADOWING – A CONSTANT RISK

- Most Common Medical Issues Masquerading as Mental Illness
  - PAIN
  - Constipation
  - Oral Health/Dental Pain
  - UTI/Infection
  - Medication side effect/Iatrogenic issue

Image Source: Deborah Sereni PsyD, Psychology Today

III: MISUNDERSTANDING BEHAVIOR – A SEPARATE RISK

- "One should not prescribe Zyprexa because a guy doesn't like his housemate."
- Environmental and social stressors can be expressed with sometimes severe aggression and SIBs.
- Risks of missing trauma history -
  - DON'T FORGET TO SCREEN FOR ABUSE AND PTSD.

CASE EXAMPLE – MISINTERPRETATION OF BEHAVIOR

- Jim, 67 y/o man with mild I/DD and MDD, sub-threshold PTSD.
- Long history of reactive depressive symptoms and SI when he felt lonely, depression treated with sertraline and mirtazapine.
- His caregivers would call 911 when he reported SI.
- He would request that his caregivers take him to the store to buy Tylenol so he could take a whole bottle and overdose.

CASE EXAMPLE – MISINTERPRETATION OF BEHAVIOR

- Loneliness and isolation worsened during pandemic - his ex-GF moved away and his favorite bus driver retired.
- More frequent complaints of SI after ComHab services were reduced, first due to closure due to pandemic and then due to critical staffing shortages.
- When he learned a family member would be potentially moving out-of-state, he again reported SI and went to a local ER. He was admitted psychiatrically and diagnosed with BPADI and started on risperidone and lithium. There was no current or prior history of mania.

CASE EXAMPLE – MISINTERPRETATION OF BEHAVIOR

- On discharge he was fatigued and had profound tremor and Parkinsonism.
- On followup interview, his SI melted away after meeting a new GF he could correspond with via postcard, he no longer complained of mood symptoms.
- Regimen consolidated with tapering risperidone to D/C and lithium D/C. Unfortunately he developed significant TD.
- He is thriving with additional social supports, and friends at church. We are currently working to manage his TD.
- FRIENDSHIPS AND SOCIAL SUPPORTS MATTER.

IV: BEST PRACTICE – MORE INFORMATION IS NEEDED IN I/DD CARE

- The biggest pitfalls can be avoided by:
  - WORKING COLLABORATIVELY
  - ENSURE ACCURATE MEDICATION LISTS
  - MULTIPLE OBSERVERS CAN HELP US GET A FULL PICTURE:

IV: BEST PRACTICE – MORE INFORMATION IS NEEDED IN I/DD CARE

- Input Needed:
  - Input from the individual we are working with!
  - Nursing staff in congregate settings
  - Family members and/or staff members that know an individual best
  - Behavioral team: staff psychologists, behavioral clinicians and day program staff
  - Collaboration and conversation with other medical providers - PCP and specialist input
  - OBJECTIVE DATA - sleep data, bowel charts, behavior data needs to be collected!
  - Baseline health and behavior information!

IV: BEST PRACTICE – MORE INFORMATION IS NEEDED IN I/DD CARE

- Also an accurate and complete medical history!
- Information gathering may need to be split into more than one visit!
- Reimbursement may be available for your extra time - Complex Care, collaboration outside a visit may not mean a loss of revenue for your clinic practice.
- “In a crisis, the first thing to do is to is to take your own pulse.”

IV: BEST PRACTICE: MAKING A DIAGNOSIS

- What are some of the diagnoses we will see?
  - ANXIETY SPECTRUM DISORDERS
    - Generalized Anxiety Disorder
    - Panic Disorder - can present with rages and aggression
    - OCD (among the most commonly co-occuring disorders in Autism)
    - PTSD - Post Traumatic Stress Disorder
- SSRIs are still first line, TCAs second line treatments

IV: BEST PRACTICE: MAKING A DIAGNOSIS

- What are some of the diagnoses we will see?
  - OTHER MOOD DISORDERS
    - Bipolar I and II Disorder (treated with mood stabilizers)
    - Major Depressive Disorder (treated with SSRI and SGA)
    - Adjustment Disorder and Reactions - Environmental changes and transitions need to be respected.
    - There are ON-LABEL THERAPIES for these as first line treatments.

IV: BEST PRACTICE: MAKING A DIAGNOSIS

- What are some of the less common diagnoses we will see?
  - CAUTION WHEN DIAGNOSING THOUGHT DISORDERS
    - HALLUCINATIONS - Reported hallucinations don't always portend schizophrenia or a psychotic disorder.
      - Complex/multimodal hallucinations need careful assessment.
      - Are they an expression of a complex fantasy or trauma? An imaginary friend?
      - Are they accompanied by periodicity related to seizures? Is it Peri-ictal?
      - Is there a delirium or toxic/metabolic encephalopathy?

IV: BEST PRACTICE: MAKING A DIAGNOSIS

- A Reminder -
  - THOUGHT DISORDERS INCLUDE
    - Schizophrenia
    - Schizoaffective Disorder
    - Delusional Disorders

IV: BEST PRACTICE: MAKING A DIAGNOSIS

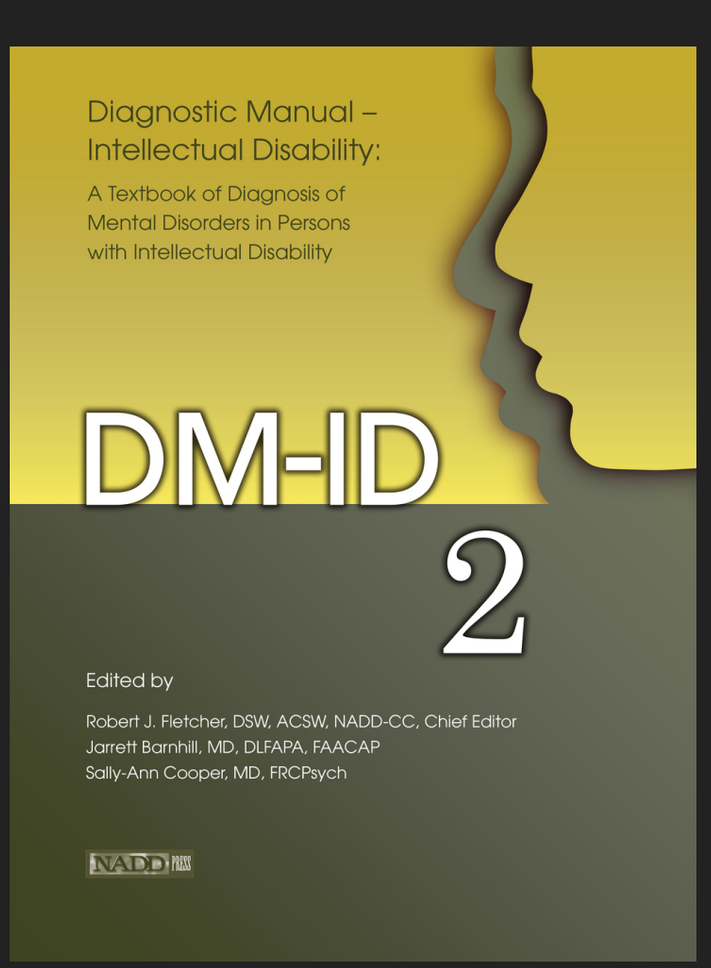
- What are some of the diagnoses we will see?
  - CAUTION WHEN DIAGNOSING THOUGHT DISORDERS
    - Persistent delusions and auditory hallucinations creating distress may represent a true thought disorder.
      - Visual hallucinations require more cautious assessment and are NOT COMMONLY seen in thought disorders.
    - Olfactory or gustatory hallucinations are more commonly related to seizures. Tactile hallucinations are most commonly seen in encephalopathy.

IV: BEST PRACTICE: MAKING A DIAGNOSIS

- NEURODEGENERATIVE DISORDERS
  - Individuals with Down Syndrome are at very high risk for Alzheimer's Disease (Tsou et al JAMA 2020)
  - Individuals with I/DD are more likely to be diagnosed with dementia.
  - It remains to be seen whether individuals with I/DD on the whole actually are at greater risk as diagnostic tools are being developed.
  - A PLUG POINTING TO MY COLLEAGUES: www.the-ntg.org

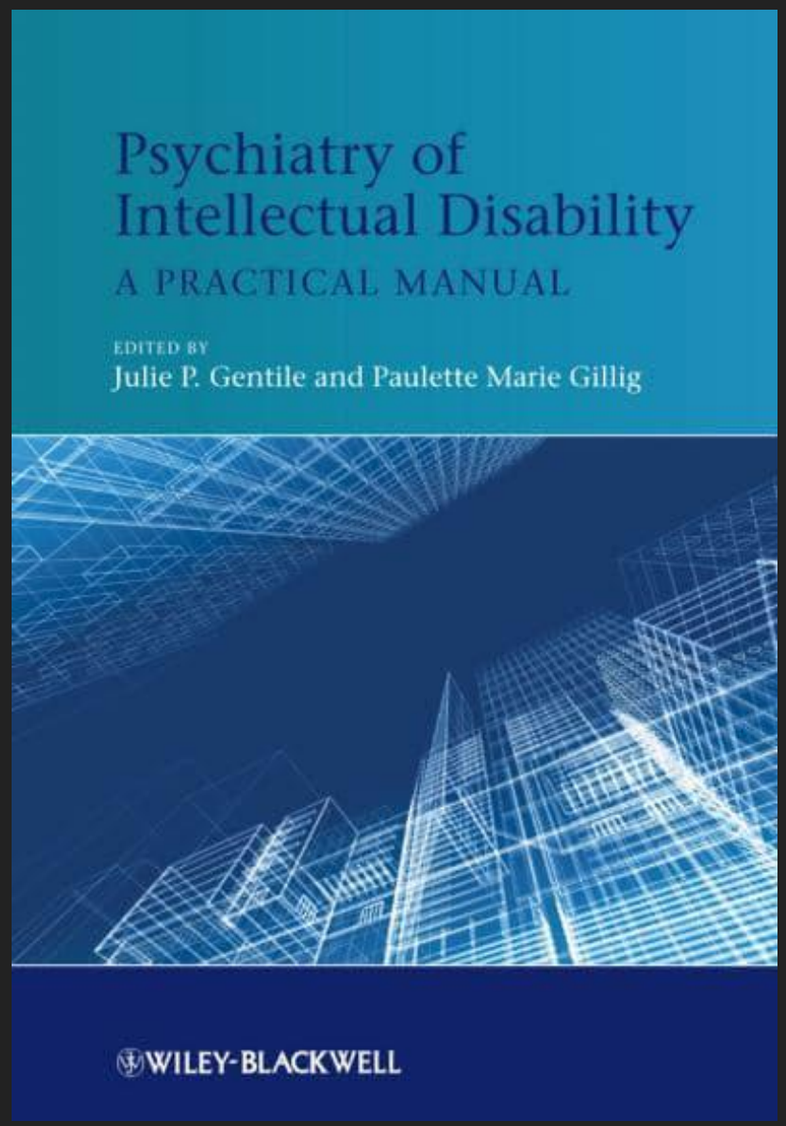
IV: BEST PRACTICE: MAKING A DIAGNOSIS

- What are resources to assist a clinician?
  - DM-ID 2 - Diagnostic Manual in Intellectual Disability - NADD Press, 2018



IV: BEST PRACTICE: MAKING A DIAGNOSIS – RESOURCES

- Psychiatry of Intellectual Disability, 2012 Wiley-Blackwell



IV: BEST PRACTICE: STARTING A MEDICATION

- EVERY MEDICATION PRESCRIBED SHOULD HAVE AN ASSOCIATED DIAGNOSIS, or CLEAR INDICATION.
- Baseline information is needed and needs be tracked with the most common classes of medications we utilize:
  - Bloodwork and serum studies
  - EKG
  - Sleep habits
  - Weight
  - Bowel habits and appetite
  - Gait and swallowing assessment

IV: BEST PRACTICE: GENERAL PRESCRIBING PRINCIPLES IN I/DD CARE

- USE NON-PHARMACOLOGIC TOOLS WHENEVER POSSIBLE
  - Environmental and Behavioral Supports are a TRUE FIRST LINE treatment for anxiety spectrum disorders.
  - Supports should be used in conjunction with medications when pharmacotherapy is needed.

IV: BEST PRACTICE: GENERAL PRESCRIBING PRINCIPLES IN I/DD CARE

- AVOID PITFALLS AND IATROGENIC INJURY
  - Extreme or Very Difficult Behaviors Associated with Illness May Lead to Rapid Titration or High Dosing
  - START LOW AND GO SLOW, BUT NOT TOO SLOW.
  - Reassess a current regimen before adding a new medication.
  - Dose medications to the person, conservatively, rather than to the degree of behavior.
  - Give adequate time to assess for benefit before titrating.

IV: BEST PRACTICE: GENERAL PRESCRIBING PRINCIPLES IN I/DD CARE

- AVOID PITFALLS AND IATROGENIC INJURY
  - Be cautious with TAPERING MEDICATION
    - SSRI discontinuation symptoms can be uncomfortable
    - Clozapine discontinuation can yield dysautonomia
    - Mood stabilizing AED discontinuation or taper can unmask epilepsy
    - Rapid discontinuation of neuroleptics or antipsychotics can yield WITHDRAWAL DYSKINESIA or AKATHISIA

IV: BEST PRACTICE: GENERAL PRESCRIBING PRINCIPLES IN I/DD CARE

- AVOID PITFALLS AND IATROGENIC INJURY
  - Avoid multiple drugs in the same class unless unavoidable.

IV: BEST PRACTICE: MONITORING

- MONITORING FOR IATROGENIC RISKS/SIDE EFFECTS IS ESPECIALLY IMPORTANT IN I/DD (NOTE THIS FOR CME)
  - Paralytic Ileus (Clozapine, SGAs, anticholinergics)
  - Hyponatremia (SSRIs)
  - Granulocytopenia (clozapine, SGAs, neuroleptics)
  - QTc Prolongation (SGAs, SSRIs, TCAs, clozapine)
  - Xerostomia/Dry Mouth (serotonergic agents)
  - Gait Changes (AEDs, neuroleptic)
  - Dyskinesia/Dystonia (neuroleptic)

CASE STUDY – DIAGNOSTIC OVERSHADOWING

- Patients can have multiple and complex problems even when following best practices.
- Irma is a 59 y/o woman with OCD and autism, hoarding behaviors, and aggressive behavior transitioned into residential care when a family member became ill and could no longer care for her.
- SSRI (Prozac) started to help with depressive symptoms (melancholia, tearfulness, weight loss, anhedonia, sleep change) and skin picking associated with anxiety during her transition to residential care, along with behavioral supports.
- Patient had stabilized on Prozac 60mg PO daily

CASE STUDY – DIAGNOSTIC OVERSHADOWING

- Behaviors and mood symptoms worsened with transition to a group home closer to her prior home, when her family member transitioned to end-of-life care.
- Our patient reported sadness and feeling generally poorly, and had weight loss, skin picking and developed severe aggression. For compulsions, off-label risperidone was added at low dose and titrated to benefit.
- Care was coordinated with her PCP at an Article 28 Clinic and her behavioral team.

CASE STUDY – DIAGNOSTIC OVERSHADOWING

- Risperidone was tapered when she developed fatigue, lethargy 3 weeks after titration from her initial presentation.
- Limited response to risperidone taper yielded two hospital admissions, leading to diagnosis of ENDOCARDITIS with chronic vegetation on her aortic valve which led to fatigue and malaise, fevers were not present.
- TAKE HOME MESSAGE: Even with vigilance, adherence to best practices and concomitant attention to coordination of care, diagnostic overshadowing is possible. Vigilance and reassessment is ALWAYS required.

V. SOME SYNDROMIC CONSIDERATIONS IN PSYCHIATRIC CARE

- Tourette - A Phenotypic Diagnosis
- Dravet Syndrome
- Trisomy 21
- Fragile X
- Prader-Willi Syndrome
- Rett Syndrome
- Tuberous Sclerosis
- 22q11 Deletion Syndrome VCFS/DiGeorge

TOURETTE SYNDROME

- Tourette Syndrome - A Phenotypic Diagnosis
- Diagnosed by the presence of multiple motor tics and AT LEAST one vocal tic.
- Tics wax and wane.
- Often accompanied by OCD, IED and ADHD
- May be present with autism or I/DD

Dr. Gilles de la Tourette

TOURETTE SYNDROME

- First and Second generation antipsychotics are first line for MOTOR TICS
- SSRIs can treat OCD
- Beta-blockade or Alpha Agonists can treat impulsivity and ADHD
- CBT/Behavioral treatments are also very useful (Pringsheim et al, Neurology 2019)

Dr. Gilles de la Tourette

CASE EXAMPLE – A SIMPLE REASSESSMENT

- Jorge is a 68 y/o man with Tourette, Moderate I/DD, minimally verbal on clozapine for many years, with compulsive aggressions.
- Careful clinical review revealed unsuccessful treatment managing aggressive compulsions and tics for many years with clozapine, and Zyprexa prior to that.
- His regimen included high dose benzodiazepine, Sinemet from an outside neurologist, Clozapine and sertraline for OCD.
- He had a history of SBO and ileus.

CASE EXAMPLE – A SIMPLE REASSESSMENT

- In light of limited benefit, a trial of a first generation antipsychotic (Prolixin) for motor tics was started, which yielded fatigue.
- Coordination of care with his team allowed for discontinuation of Sinemet (he had no Parkinsonism and did not have Parkinson's disease). Prolixin was switched to Risperidone.
- Patient's compulsions were stabilized for about 4 months on risperidone 3mg PO daily, and SSRI and clozapine were successfully discontinued.

CASE EXAMPLE – A SIMPLE REASSESSMENT

- Symptoms and Severity of compulsions waxed and waned.
- Self-injurious tics re-emerged and risperidone was titrated to 8mg daily dose over time.
- SECOND ANTIPSYCHOTIC was added (haloperidol) monitoring cautiously, after review of prior treatments.
- A WORD ON ANTIPSYCHOTIC MONOTHERAPY VS. POLYPHARMACY

ANTIPSYCHOTIC MONO THERAPY VS. DUAL ANTIPSYCHOTICS

- Historically, polypharmacy has placed individuals at great risk of cardiac events and neuroleptic malignant syndrome due to 2 or even 3 antipsychotic medications at a time being prescribed.
- It is always best practice to use 1 medication rather than 2.
- Sometimes multiple trials of neuroleptic monotherapy are not effective.
- IN SOME CASES, we learn during cross-titration that dual therapy is necessary and well-tolerated.

ANTIPSYCHOTIC MONO THERAPY VS. DUAL ANTIPSYCHOTICS

- Sometimes first generation antipsychotic with second generation antipsychotic proves helpful
- Sometimes full D2 antagonist with partial D2 agonist is used.
- Note this is not a recommendation - this is a description and information about what is being utilized to manage sometimes life threatening compulsions in some individuals.
- SAFETY RECONSIDERATION -
  - Evidence from Finland National Database showed that antipsychotic monotherapy was not necessarily safer than dual therapy (Taipele Amer J of Psychiatry 2023).

ANTIPSYCHOTIC MONO THERAPY VS. DUAL ANTIPSYCHOTICS

- Jorge has stabilized and no longer has compulsive aggressions, on dual antipsychotic therapy.
- Emergent depressive symptoms and sudden bouts of tearfulness have been managed with TCA (anafranil) for emotional incontinence and OCD, CAUTIOUSLY given his age, and historical lack of benefit from SSRIs.
- He has returned to program and is doing well.

DRAVET SYNDROME

- SCN1A or SCN2A Sodium Channel Mutation
- Most often Diagnosed in Childhood, with severe febrile seizures.
- Often accompanied by behavioral and mood dysregulation, anxiety disorders.
- SODIUM CHANNEL MOOD STABILIZING AGENTS SUCH AS CARBAMAZEPINE (TEGRETOL) ARE CONTRAINDICATED

Brian, Living with Dravet Syndrome

(dravetfoundation.org, Dravet Stories)

DOWN SYNDROME – TRISOMY 21

- 1:800 live births in US
- May be accompanied by autism
- Clinically - important to screen for and manage contributing factors to mood and behavior:
  - Aspiration
  - Cataract
  - Chronic Constipation
  - Dementia (APP)
  - Sleep Apnea
  - Seizures

Chris Burke

DOWN SYNDROME – TRISOMY 21

Kayla McKeon, NDSS Self-Advocate and Barbie Consultant

FRAGILE X (FMR1)

- 1:4000 males, 1:8000 females
- Dominant -inheritance - CGG trinucleotide expansion in FMR1 gene on X chromosome
- Long facies, low set ears, macro-orchidism in males.
- Frequent Behavioral Considerations:
  - Autism in 1/3 of those affected
  - Hyperactivity, inattention and impulsivity
- Managing Anxiety is Key for treating Fragile X!
- Pay attention to gait and cognition, Fragile X Associated Ataxia.

Photo - Roger Ballen

PRADER-WILLI

- Occurs in 1:15,000 births
- Chromosome 15q11.2-13 loss, usually paternal.
- Associated with short stature, hypotonia, mild I/DD, and hyperphagia/obesity
- Food-seeking, OCD, anxiety and SIBs (skin picking) are very common.
- Anxiety management best with agents that don't have associated weight gain and appetite increase (Butler et al, Curr Led Rev 2016)

Image Source - "Prader-Willi and Not Feasting at Christmas" BBC News, Dec 23 2014

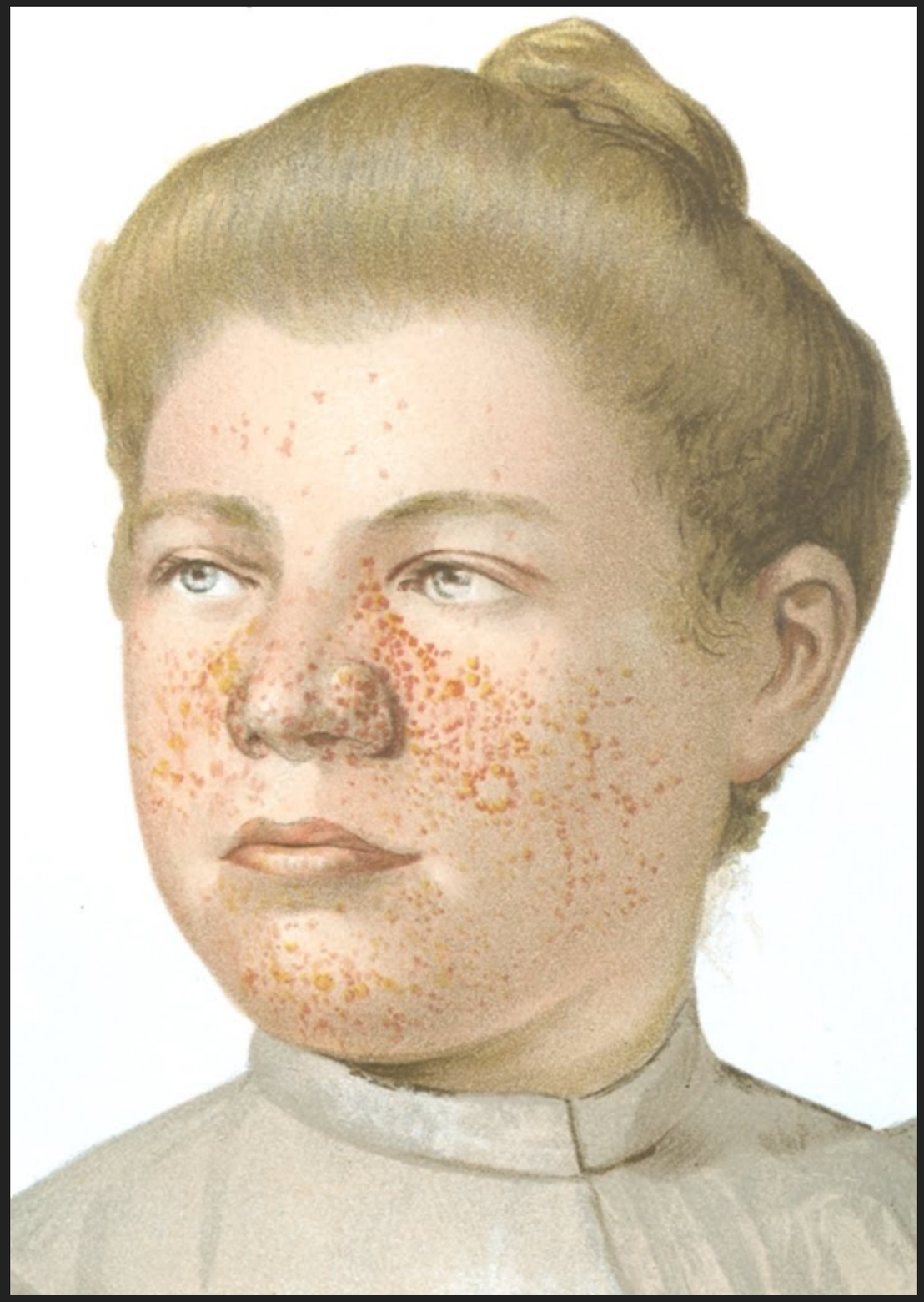
RETT SYNDROME (MECP2)

- A genetically defined X-Linked syndrome in both sexes - presenting more as autism in surviving males (Zogby)
- 1:8500 Live Female Births in US
- Classically seen in females with-
  - Hand wringing
  - Scoliosis
  - Epilepsy
  - Autism
  - GERD (severe)
  - Loss of milestones beginning at 6 months
- Behavioral management of sometimes severe SIBs related to anxiety and autism is often needed.
- Now a single targeted treatment (Daybue, trofinetide) is available to treat Rett.

Source - Vancouver Sun, 19 y/o F with MECP2

TUBEROUS SCLEROSIS

- 1:6,000 newborns in US
- Epilepsy
- Anxiety
- Autism
- Self injurious behaviors
- Giant cell astrocytomas, hamartomas ("tubers" if cortical)
  - *hydrocephalus*
- Autosomal Dominant TSC1 and TSC2 tumor suppressor gene mutations
- IMPORTANT TO AVOID OVERSHADOWING IN TS PATIENTS - headaches and behavior can be a symptom of obstructed CSF



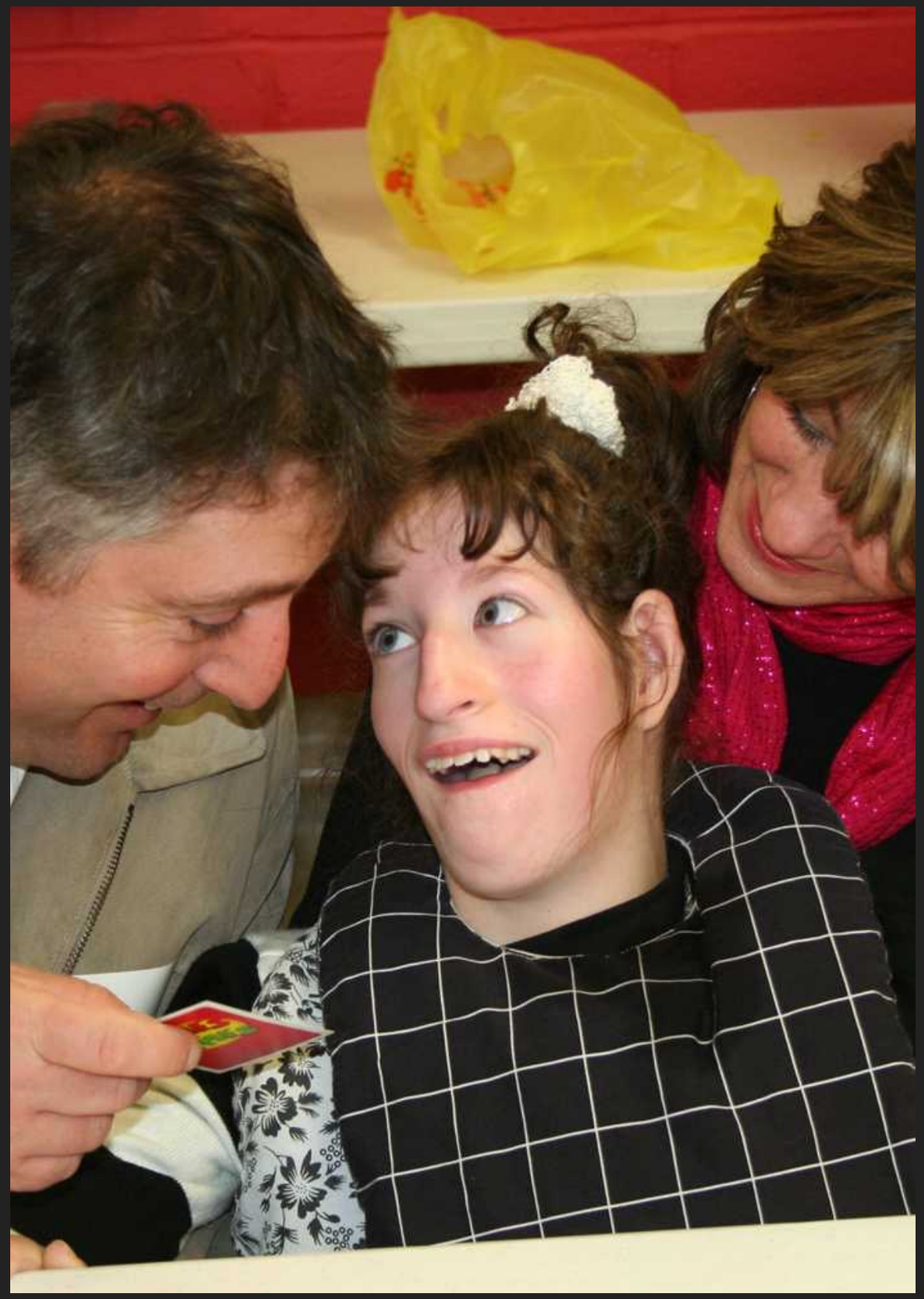
22Q11.2 SYNDROME/VCFS

- A syndrome with many names (DiGeorge, VCFS, Shprintzen Syndrome) - 1:1000 live births
- May be the result of a deletion OR duplication
- Cleft palate, Multiple Cardiac Malformations, Hypoparathyroidism, immunodeficiency
- Clear link to bipolar disorder
- May have associated anxiety and OCD/ Autism
- May be more likely to develop Parkinsonism due to co-location of COMT mutations.
- vcfscenter.com is a free resource that provides consultative services.

Elisabeth, living with 22q11.2 Syndrome - Source 22q.org

VI. TOGETHER WE CAN MAKE A DIFFERENCE

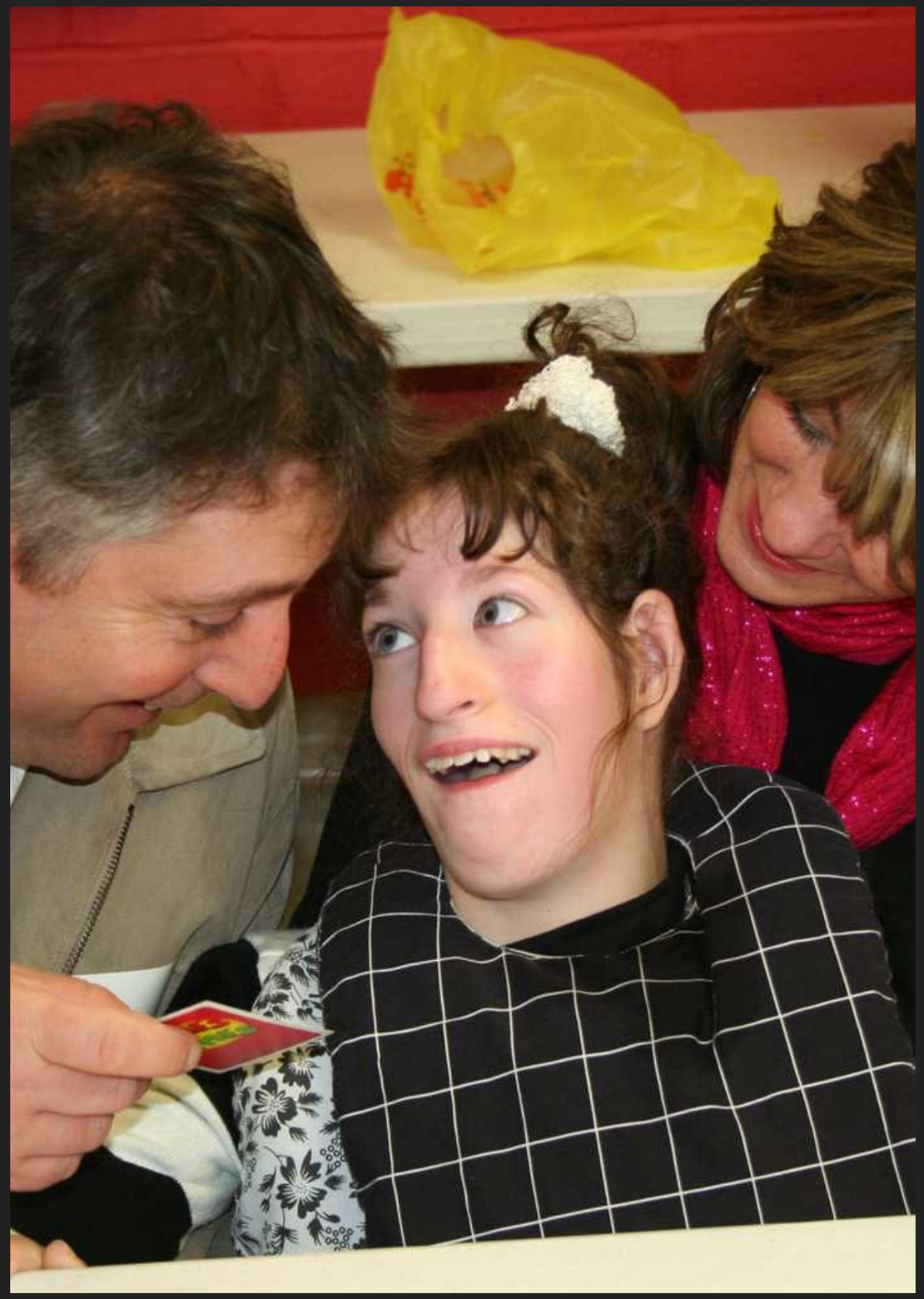
- IN THE FUTURE we can tackle the following:
- Lack of availability of inpatient care for the individuals we serve (some behavioral health units have IQ cutoffs)
- Lack of access to ECT for Catatonia
- Lack of Data using DM-ID 2 criteria



Late adolescent with 5p-, Cri-Du-Chat

VI. TOGETHER WE CAN MAKE A DIFFERENCE

- A NOTE ON TRUST AND COLLABORATION -
  - "There's a reason the individual is in my office."
- We ARE here to help.
- Expertise and experience need to be respected bidirectionally.
- COMMUNICATION and EDUCATION can help dissolve historical mistrust and fears.



Late adolescent with 5p-, Cri-Du-Chat

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THANK YOU FOR YOUR ATTENTION! QUESTIONS?

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