

# MEDICATIONS IN X&Y CHROMOSOME VARIATIONS

## MAKING MEDICATION DECISIONS

&

## STRATEGIES TO SET AND MONITOR TREATMENT GOALS

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# OUTLINE

**OVERVIEW OF CONDITIONS TREATED WITH MEDICATIONS**

**MAKING DECISIONS ABOUT MEDICATIONS**

**SYMPTOMS TREATED WITH MEDICATIONS**

**NUTS AND BOLTS:**

**STARTING MEDICATIONS**

**DEVELOPING TREATMENT GOALS**

**MONITORING RESPONSE AND SIDE EFFECTS**

**INTRODUCTION TO MEDICATION CLASSES**

**RESOURCES**

**CASE EXAMPLES**



# DISCLAIMER / DISCLOSURES

**I'm not endorsing any specific medication, brand, or company**

**I have received research funding for Fragile X research from:**

**Seaside, Roche, Neuren, Alcobra**

**I have consulted for:**

**Novartis, Zynerva, Ovid**

**All medications should be discussed with your doctor**

**We cannot make specific recommendations without evaluating a patient**

**XYY, XXX, XXYY, XXY,  
etc**

**Differences in Brain  
Development / Function**

**INCREASED RISK FOR:**

**Cognitive / Learning Differences**

**Developmental Delay  
Learning Disability (LD)  
Intellectual Disability (ID)**

**Social Development Differences**

**Social immaturity  
Autism Spectrum Disorder (ASD)**

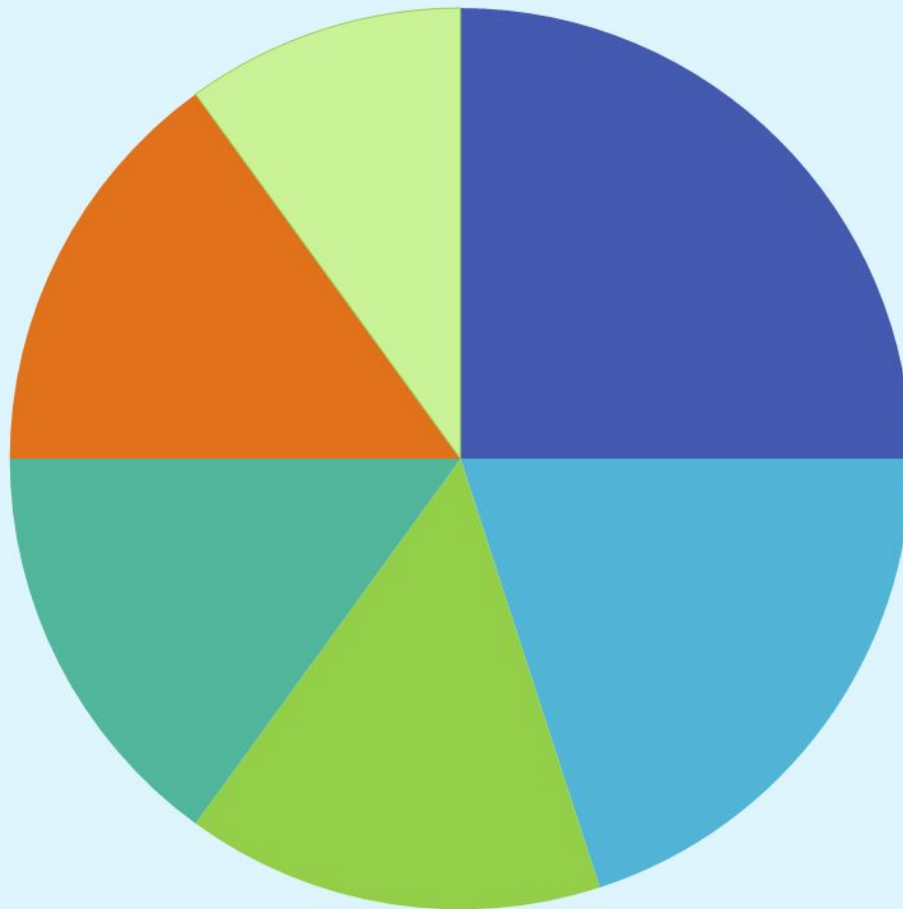
**INCREASED RISK FOR:**

**Behavioral / Emotional Differences**

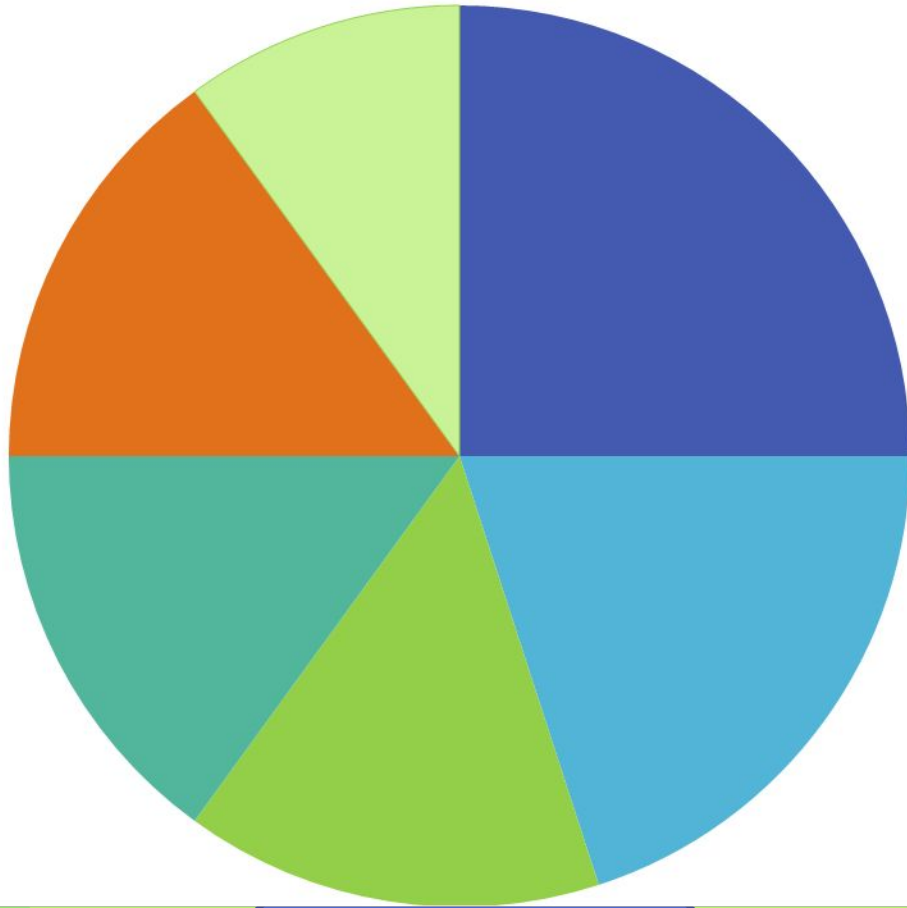
**Short Attention Span  
Distractibility  
Hyperactivity  
Impulsivity** ———— **ADHD**

**Anxiety  
Depression  
Sensory Sensitivities  
Irritability / Aggression  
Obsessive-Compulsive Behaviors  
Repetitive / Stereotypic Behaviors**

# TREATMENT PLAN



- Academic supports
- OT
- Speech
- Behavior Therapy
- Medications
- Other



- Academic supports
- OT
- Speech
- Behavior Therapy
- Medications
- Other

**Family / Home Environment**

# WHEN SHOULD MEDICATIONS BE CONSIDERED?

- When behavioral/emotional difficulty is significantly impacting:
  - Health and Safety
  - Academics / Learning
  - Therapies
  - Participation in the family / community
  - Social development / Social Interactions


When child is expressing / demonstrating distress about the emotion/behavior

# COMMON PARENTAL CONCERNS


???



# COMMON PARENTAL CONCERNS

- I don't want my child to become dependent on them or addicted to them
  - I don't want my child to be "drugged"
  - I don't want to change his/her personality
  - I am worried medications will change the way the brain develops
- 

# COMMON PARENTAL CONCERNS

- I'm worried about side effects
  - He/she will have to take it for life
  - Family member/friend took them and had a bad reaction
  - I read about a person who took them and...
  - I want my child to learn to manage his/her own behaviors without needing medications
- 

# WHEN SHOULD MEDICATIONS BE CONSIDERED?

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- Health and Safety
- Academics / Learning
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- Functioning in the family / community
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When child is expressing / demonstrating distress about the emotion/behavior

# WHEN SHOULD MEDICATIONS BE CONSIDERED?

When behavioral/emotional difficulty is significantly impacting:

## ▪ Health and Safety

**Injuries: To self and others (Aggression / Self-Injurious Behaviors)**

**Risk of Injuries: To self and others (Aggression / Self-injury / Running off / Impulsive Behaviors)**

**Health:**

**- Poor growth/Weight gain (attention span w/meals, restricted eating due to sensory or anxiety concerns with food / eating environment)**

**- Constipation / GI issues (anxiety / refusal to poop at school)**

# WHEN SHOULD MEDICATIONS BE CONSIDERED?

When behavioral/emotional difficulty is significantly impacting:

- Academics / Learning
- Therapies
- **How much time is spent in managing “behavior” (attention span, anxiety, etc.) versus engaged in the learning/school environment or therapy?**
- **Are they making the rate of progress that they are capable of in academic / therapy environments?**

**Is their academic placement or availability of therapy limited by their behavior?**

# WHEN SHOULD MEDICATIONS BE CONSIDERED?

When behavioral/emotional difficulty is significantly impacting:

- Functioning in the family / community
- **Causing significant conflict with siblings / family**
- **Not able to participate in family / community events**
- **Family not participating in family / community events**

# WHEN SHOULD MEDICATIONS BE CONSIDERED?

- When behavioral/emotional difficulty is significantly impacting:

- Social development / Social Interactions

**Impulsivity / Attention Span affecting social interactions / play**

- “Annoying” or “Not fun to play with”

- “Long term memory” of negative behaviors in kids

  - “She’s the girl who....”

  - “He’s the kid who...”

**Anxiety / Social Withdrawal / Selective Mutism**

- Limited ability to have / engage in social interactions

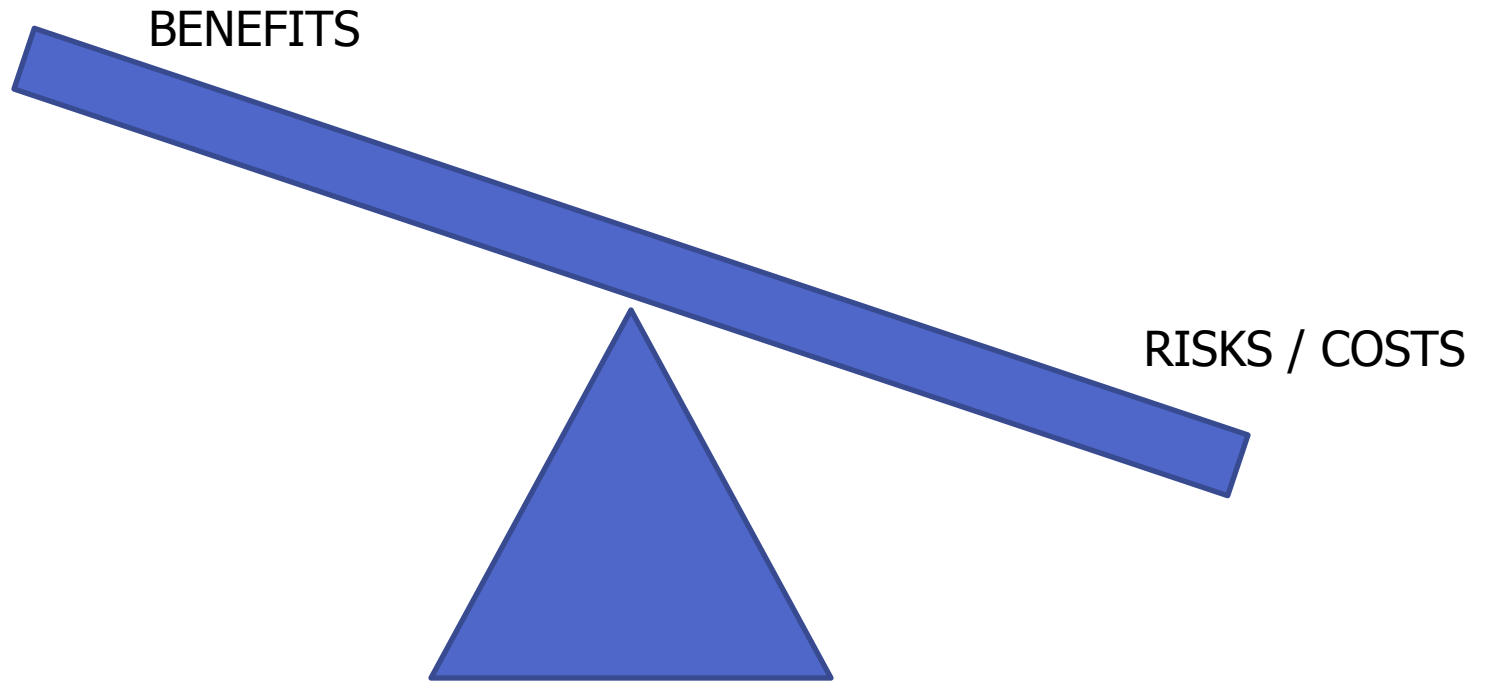
- Limited ability to have / engage in social activities

# WHEN SHOULD MEDICATIONS BE CONSIDERED?

- When behavioral/emotional difficulty is significantly impacting:
- **When child is expressing / demonstrating distress about the behavior**
  - “Why is this happening?”
  - “I don’t like...” / “I can’t help it”
  - Self-injury
  - Suicidal ideation / attempt



# CONSIDERATIONS FOR STARTING TREATMENTS



# BENEFITS

# RISKS

TAKING MEDICATION

A large, empty rectangular box with a thin green border, intended for listing the benefits of taking medication.A large, empty rectangular box with a thin green border, intended for listing the risks of taking medication.

NOT TAKING MEDICATION

A large, empty rectangular box with a thin green border, intended for listing the benefits of not taking medication.A large, empty rectangular box with a thin green border, intended for listing the risks of not taking medication.

# BENEFITS

# RISKS

TAKING MEDICATION

**Behavior might improve**

**Overall functioning may improve at home, in school / work, in community**

**Improvement in social interactions / with others / social opportunities**

**Feeling that you are doing everything you can to help your child**

**Side Effects / Long term effects**

**Medication may not work**

**Medication may worsen other behavior**

**Feeling that it is the “easy way out”, you are not helping your child to learn to regulate behavior on their own**

**Costs / Appointments**

**Lab draws / Monitoring distressful**

NOT TAKING MEDICATION

**Avoid side effects and cost**

**Avoid worries of side effects**

**You may find other treatments / supports to help the problem**

**If behaviors continue to be a problem, you can consider them later**

**Behavior can continue to cause problems / stress for patient, in family, in school / work setting**

**Behavior may get worse**

**Behavior may limit opportunities**

**Behavior may limit progress in school / therapies**

**Behavior may cause health / safety problems**

# TIMING OF STARTING MEDICATIONS

**Symptoms present**



**Symptoms causing mild-to-moderate impairment/problems**



**Symptoms causing moderate-to-severe impairment/problems**



**CRISIS**

**Academic Failure**

**Severe safety concerns / injuries**

**Kicked out of school**

**Mental Health Hospitalization**

# TIMING OF STARTING MEDICATIONS

## **Medications as “the last option”**

- Safety concerns
- Impact of prolonged severe behavioral difficulties and stress on:
  - Self (Child / Adult with XY variation)
  - Family relationships
  - Social relationships
  - Academic placements / relationships
  - Long term physical and mental health

# CONSIDER MEDICAL PROBLEMS CONTRIBUTING TO BEHAVIOR DIFFICULTY

## Consider / Rule-Out:

**Pain – ear infections / dental problems**

**Constipation / GI symptoms**

**Headaches**

**Vision / Hearing problems**

**Seizures**

**Thyroid problems**

**Sleep apnea**

# DECISION: MEDICATION TRIAL

**Now what?**

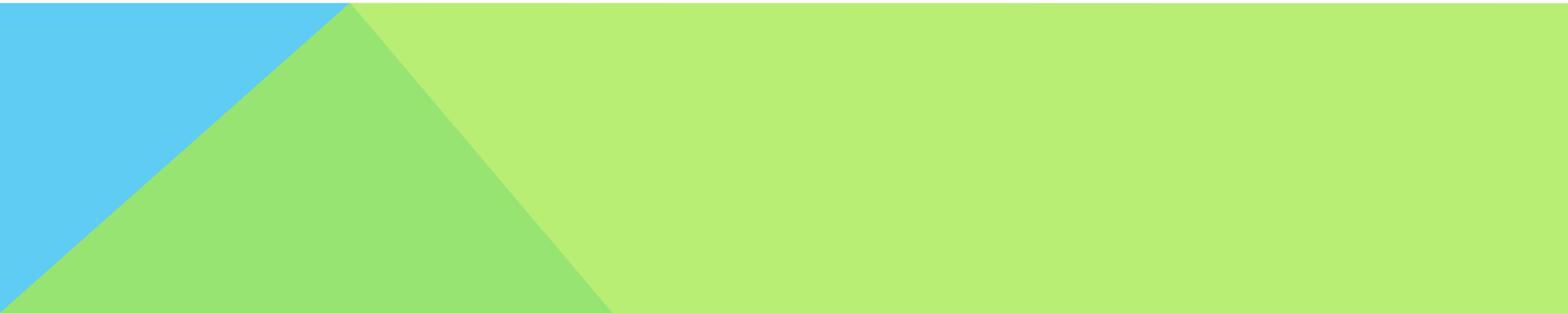


# IDENTIFYING TARGET BEHAVIORS

**What is the goal of medication treatment?**

**What would you like to see improve?**

**What behavioral / emotional difficulty is leading to impairment in overall functioning?**





**XYY, XXX, XXYY, XXY,  
etc**

**Differences in Brain  
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(OCD)  
Repetitive / Stereotypic Behaviors**

# IDENTIFYING TARGET BEHAVIORS

**7 year old boy with XXY (Albert):**

**“Behavior is getting worse, the school keeps calling me because of his behavior, going to the grocery store or restaurant with him is horrible and we don’t go anymore, he almost got hit by a car yesterday in the parking lot, he got kicked out of speech therapy”**

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**CONSIDERATIONS FOR MEDICATIONS:**

**SAFETY???**

**ACADEMICS / THERAPY???**

**FAMILY / COMMUNITY FUNCTIONING???**

**WHICH MEDICATION?**

**WE NEED MORE DETAILS / SPECIFICS**

# IDENTIFYING TARGET BEHAVIORS

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**“Behavior is getting worse, the school keeps calling me because of his behavior, going to the grocery store or restaurant with him is horrible and we don’t go anymore, he almost got hit by a car yesterday in the parking lot, he got kicked out of speech therapy”**

**CONSIDERATIONS FOR MEDICATIONS:**

**SAFETY: YES**

**ACADEMICS / THERAPY: YES**

**FAMILY / COMMUNITY FUNCTIONING: YES**

**WHICH MEDICATION?**

**WE NEED MORE DETAILS / SPECIFICS**

# TARGET BEHAVIORS

**“The school keeps calling me because of his behavior”**

**Why?**

**1. He can't sit through group activities / “circle time”, the teacher always needs to redirect him to his work, he gets out of his seat, he grabs belongings of other students**



**OR**

**2. He has meltdowns every time he transitions and “gets stuck”, he's overwhelmed in the classroom, when he doesn't want to do something he walks out of the room, becomes disruptive with peers**



# TARGET BEHAVIORS

**“Going to the grocery store or restaurant is horrible”**

**Why?**

**1. He can't sit still / hyperactivity / touches or grabs everything, runs down the aisle, yells when he can't get something he wants**



**OR**

**2. Gets overwhelmed in busy places, doesn't like new places / change in routine, asks over and over when we are going home, then melts down after 5-10 minutes**



# TARGET BEHAVIORS

**“He almost got hit by a car in the parking lot”**

**Why?**



- 1. He ran off when he saw the ice cream store he wanted go in**

**OR**



- 2. He ran off when he saw he was at the dentist office**

# TARGET BEHAVIORS

**“He got kicked out of speech therapy”**



**Why?**

**1. He likes her but he can't pay attention long enough to do what the therapist wants him to do, he keeps getting out of his chair, touching all her materials, she spends all of the visit trying to get him to get through a couple exercises or redirecting him**



**OR**

**2. He becomes agitated in that small room, she talks loudly and it's painted in bright colors, he's frustrated and overwhelmed within 5-10 minutes, and then he melts down or “we lose him” for the rest of the session**



# TARGET BEHAVIORS



**TARGET BEHAVIOR: Attention Span / Hyperactivity / Impulsivity**

**MEDICATION CONSIDERATION: ADHD Medication**

**MONITOR RESPONSE TO MEDICATION:**

**Improved attention span at school and during therapy (from 1-2 minutes currently to \_\_\_ minutes)**

**Ability to tolerate going to the grocery store / restaurant (i.e. less fidgety / able to tolerate short trips without a meltdown)**

**Decreased impulsivity (less grabby, less interrupting others, less running off/unsafe impulsive behaviors)**

# TARGET BEHAVIORS



## Boy #2

**TARGET BEHAVIOR: Anxiety**

**MEDICATION CONSIDERATION: Anxiety Medication**

**MONITOR RESPONSE TO MEDICATION:**

**Better able to tolerate transitions**

**Decreased vocalizations / rocking when overwhelmed**

**More flexible with changes, new places and changes in routine / fewer meltdowns**

**Fewer “panic” reactions leading to safety risks**

# MEDICATION TREATMENT PLAN

**Identify target behaviors and determine how to measure them**

- Frequency
- Duration
- Intensity
- Formal/Standardized vs. Observational/"Informal"

# MEDICATION TREATMENT PLAN

## Treatment Plan:

- TEAM
  - TEAM CAPTAIN – Individual taking the medication
  - TEAM Members – 1-4 people to help monitor response to medication
    - Parent/caretaker, teacher, friend, therapist / psychologist, siblings

Medication Treatment Plan ¶

TEAM CAPTAIN: → → → → TEAM MEMBERS: → → → → ¶

→ → → → → → → → → → → ¶

→ → → → → → → → → → → ¶

→ → → → → → → → → → → ¶

¶

Target Behavior/Symptom: ¶

Medication Name/Dose: ¶

¶

How will I know it is working? (Specific Target behaviors/symptoms) ¶

1. ¶

2. ¶

3. ¶

Side Effects to Watch for: ¶

1. ¶

2. ¶

3. ¶

If I have concerns call: ¶

→ 911 – Emergency ¶

→ Clinic Phone: ¶

→ After Hours/Doctor on Call: ¶

For Refills call: ¶

# MONITORING RESPONSE TO TREATMENT

## Monitoring Tools:

**Standardized Questionnaires**

**ADHD symptoms**

**Others...**

**Completed by:**

**Parents**

**Teachers**

**Therapists / Other providers**

# MONITORING RESPONSE TO TREATMENT

Parent's Name: \_\_\_\_\_ Today's Date: \_\_\_\_\_ Child's Name: \_\_\_\_\_ Age: \_\_\_\_\_

Directions: Each rating should be considered in the context of what is appropriate for the age of your child and should reflect that child's behavior in the last 6 months.

Is this evaluation based on a time when the child  was on medication  was not on medication  not sure?

BEHAVIOR:	never	occasionally	often	very often
1. Does not pay attention to details or makes careless mistakes; for example, homework.	0	1	2	3
2. Has difficulty attending to what needs to be done.	0	1	2	3
3. Does not seem to listen when spoken to directly.	0	1	2	3
4. Does not follow through when given directions and fails to finish things.	0	1	2	3
5. Has difficulty organizing tasks and activities.	0	1	2	3
6. Avoids, dislikes, or does not want to start tasks that require ongoing mental effort.	0	1	2	3
7. Loses things needed for tasks or activities (assignments, pencils, or books).	0	1	2	3
8. Is easily distracted by noises or other things.	0	1	2	3
9. Is forgetful in daily activities.	0	1	2	3
10. Fidgets with hands or feet or squirms in seat.	0	1	2	3
11. Leaves seat when he/she is supposed to stay in his/her seat.	0	1	2	3
12. Runs about or climbs too much when he/she is supposed to stay seated.	0	1	2	3
13. Has difficulty playing or starting quiet games.	0	1	2	3
14. Is "on the go" or often acts as if "driven by a motor".	0	1	2	3
15. Talks too much.	0	1	2	3
16. Blurts out answers before questions have been completed.	0	1	2	3
17. Has difficulty waiting for his/her turn.	0	1	2	3
18. Interrupts or bothers others when they are talking or playing games.	0	1	2	3
19. Argues with adults.	0	1	2	3
20. Loses temper.	0	1	2	3
21. Actively disobeys or refuses to follow an adult's requests or rules.	0	1	2	3
22. Bothers people on purpose.	0	1	2	3

# MONITORING RESPONSE TO TREATMENT

## Monitoring Tools:

### 2. Behavior Logs

Formal behavior logs in the school setting

Parent-developed logs / tracking systems

- At time of each incident

- Daily ratings each night

(Green, Yellow, Red days)

Communication notebooks with schools

OT / Speech / PT Therapy reports

# FINDING A DOCTOR

Primary Care Doctor

Referral from Primary Care Doctor

Developmental Pediatrician

Child Adolescent Psychiatry

Developmental Neurology

Referrals from local Family Groups / Autism groups

AXYS Clinic & Research Consortium Clinic





# FINDING A DOCTOR

Who can't prescribe medications?\*

Psychologists

Teachers

Therapists (OT, Speech, PT)

\*But, they can all be very helpful as part of team monitoring effects of medication

# DIFFERENT STYLES OF DOCTORS

Authoritative  
“Father / Mother Figure”  
Dictator



Collaborative  
Partner  
Consultant  
Team Member

ALSO:  
DIFFERENT STYLES OF PATIENTS

# HELP YOUR DOCTOR BE A GOOD DOCTOR

**Come to appointment with:**

**Ideas of specific treatment goals**

**Specific examples of difficult behaviors**

**Behavior logs (if available)**

**Written questions (2-4)**

**Written input from teachers**

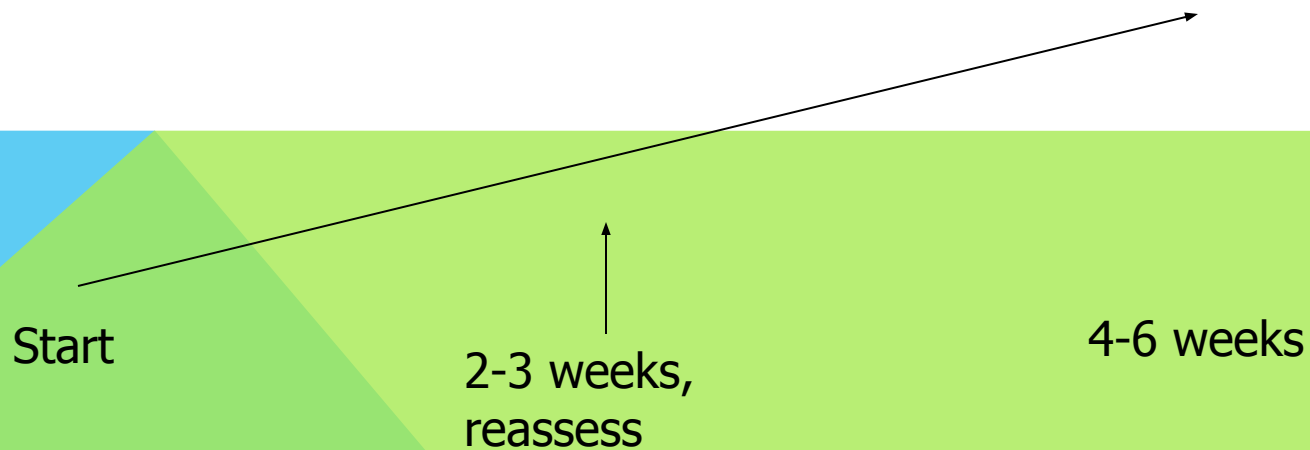
**Copies of reports from any medical evaluation / psychology or therapy progress results, IEPs since last visit**

# STARTING MEDICATIONS

**Start low, go slow**

**One change at a time**

- No other changes in meds, therapies or environment
- Summer / school breaks



# IMPORTANT QUESTIONS TO ASK

**What are the common side effects?**

**What are the rare side effects to watch for?**

**If side effects happen, what should we do?**

**How/who do I contact if I am concerned about the effects of the medications?**

- During the day?
- After hours / weekends?

**Does the medication need to be taken every day?**

**What should I do if he/she misses a dose?**

**What if I run out or want to stop – is it dangerous to stop abruptly?**

# MONITORING MEDICATIONS

## Follow-up Visits

Necessary at certain frequencies

Range from every 1-6 months to yearly

Allow doctor to see and examine patient

Physical Examination (other medical problems / findings)

Observe response to treatment

Side effect monitoring

Lab monitoring

Can be done without patient present (pediatrics)

## Phone calls

OK for adjustments / updates/ mild difficulties

Sometimes necessary if physically far from provider

Not billable

## Behavioral / Emotional Differences

**Short Attention Span  
Hyperactivity  
Impulsivity**



**ADHD Medications  
Stimulants  
Nonstimulants**

**Anxiety**



**SSRI Medications  
Alpha agonists**

**Irritability / Aggression  
Self-injurious Behavior**



**SSRI Medications  
Atypical Antipsychotics  
Mood Stabilizers**

**Obsessive-Compulsive Behaviors (OCD)**



**SSRI Medications**

# ATTENTION PROBLEMS ARE NOT ALWAYS ADHD...

Also consider:

Learning / Cognitive Impairments

Anxiety

Sensory sensitivities

Medical considerations:

Vision

Hearing

Thyroid problems

Seizure disorders

Sleep apnea



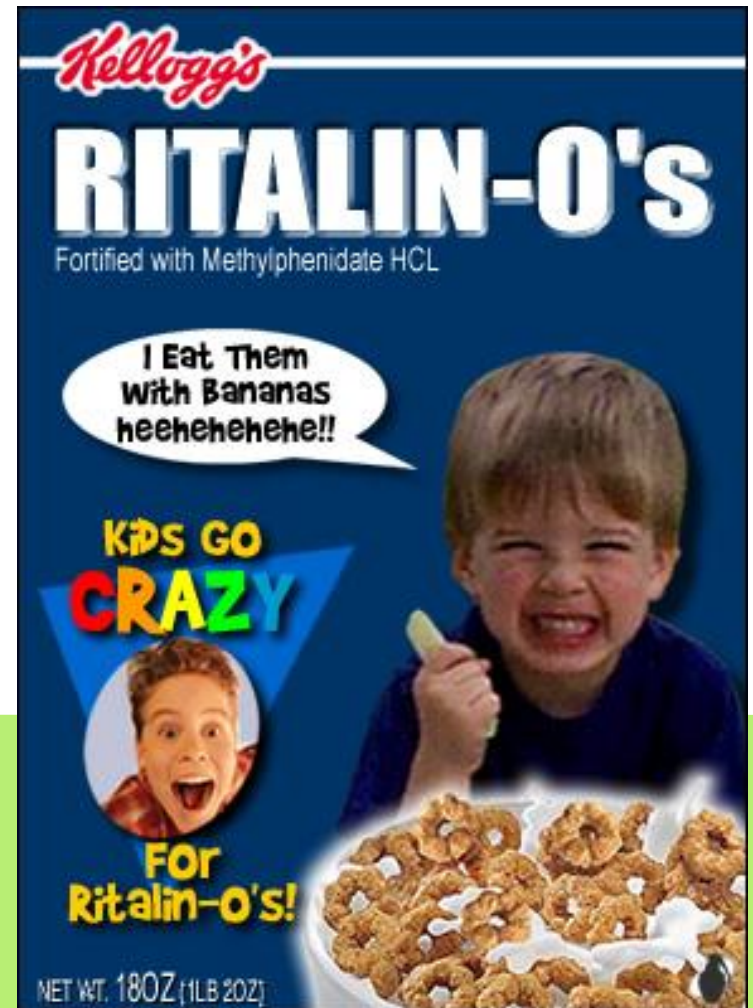
# MEDICATIONS FOR ADHD

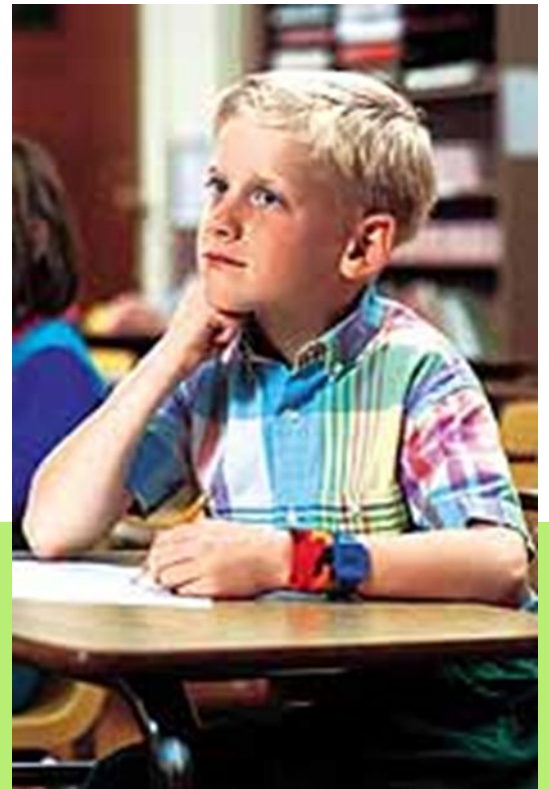
## Stimulants

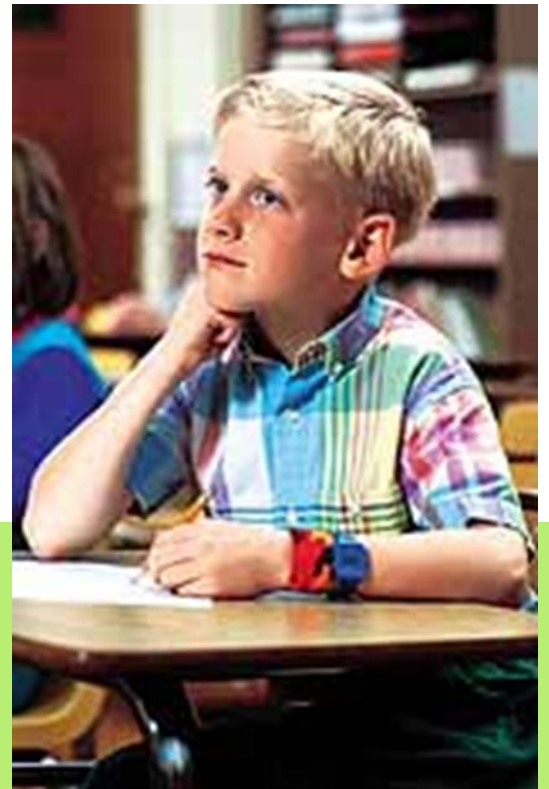
- Methylphenidate
  - Ritalin, Concerta, Metadate, Focalin
- Dexedrine / Adderall / Vyvanse

## Nonstimulants

- atomoxetine (Strattera)
- guanfacine (Intuniv)
- clonidine (Catapres, Kapvay)
- bupropion (Wellbutrin)

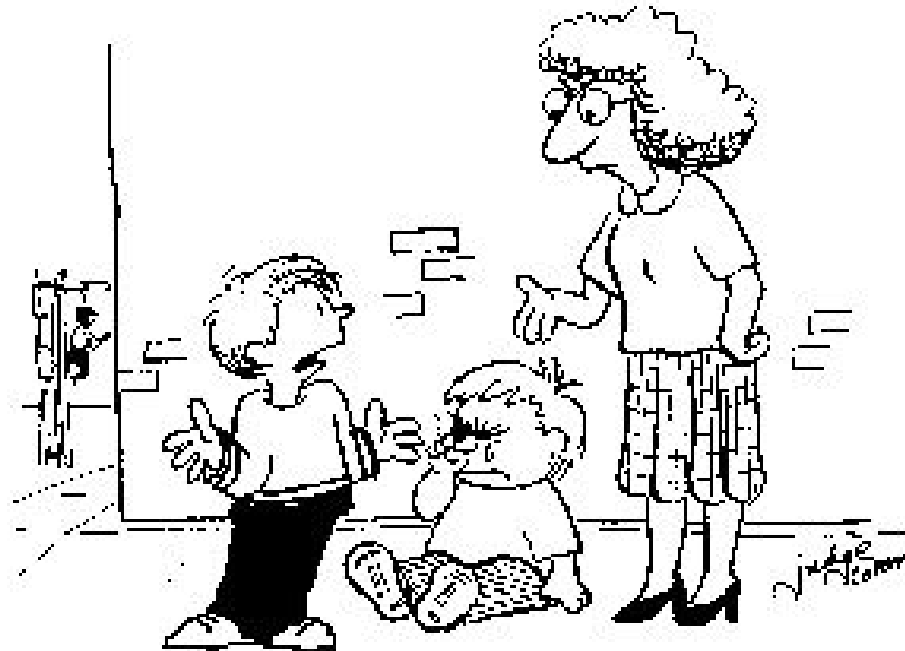






# MEDICATIONS FOR ANXIETY

judcohen@erols.com ©'97



"I couldn't help it. My lack of serotonin made me do it."

# SSRIS

- Anxiety
- Shyness
- Withdrawal
- Worries / Fears
- Panic Attacks
- Irritability
- Depression

Examples:  
citalopram (Celexa)  
escitalopram (Lexapro)  
sertraline (Zoloft)  
fluoxetine (Prozac)

**Mechanism: Increase brain  
serotonin levels**



# SSRIS – POTENTIAL BENEFITS

**less irritability, improved mood, fewer outbursts with anxiety trigger**

**able to transition more easily**

**less self-picking, nailbiting, other behaviors**

**Fewer worries, perseverations**

**able to tolerate changes / frustrations more easily**

**able to be more comfortable in social settings**

**some show increased speech if selective mutism or anxiety component to low speech**

**less fixations and compulsive behaviors**

**Less tearfulness / emotional sensitivity “easy to cry”**



# SSRIS - SIDE EFFECTS

**activation/hyperactivity/disinhibition - wild/odd behaviors – about 10-15%**

**appetite changes**

**insomnia - usually wears off**

**nausea - not common**

**decreased sexual drive/impotence - rarely an issue**

# OTHER MEDICATION TREATMENTS

## **Atypical Neuroleptics (Atypical Antipsychotics)**

- Risperdal (risperidone)
- Abilify (aripiprazole)
- Seroquel (quetiapine)
- Others

## **Mood Stabilizers**

- Lithium
  - Depakote
  - Trileptal
  - Lamictal
- 



# QUESTIONS....

