



Mass General Brigham
Mass General for Children

LURIE CENTER FOR AUTISM

Depression in Down syndrome

Robyn Thom, MD

Michelle L Palumbo, MD

Laura Sarnie, MPH

Depression

- **More common in adults with DS than in children with DS**
 - Awareness of differences, relationship loss**
- **Between 6 to 18%, with a generally accepted central lifetime estimate of approximately 10%**
- **In a large population-based case-control study of 6,078 individuals with DS, people (0-89 years old) with DS had a **1.27-times** greater likelihood of developing depression**
- **Important to rule out medical causes**
 - **Sleep apnea**
 - **Hypothyroidism**

Thom RP, et al. *Brain Sci.* 2021 Sep 15;11(9):1216.;
Rivelli A, et al. *J Patient-Centered Res Rev.* 2022;9(1):58–63.



Depression

- **Symptoms of depression in DS can be similar to that seen in adults without DS.**
 - **Sadness**
 - **Loss of interest or pleasure**
 - **Appetite changes**
 - **Decreased energy**
 - **Cognitive changes (i.e. concentration, memory loss)**
 - **Psychomotor slowing or agitation**
 - **Feelings of hopelessness, worthlessness**
 - **Suicidal ideation**
- **Additional symptoms of depression in people with DS can include a **loss of self-care skills, social withdrawal, somatic complaints, aggression, and decreased speech.****
- **May have more challenges expressing feelings of worthlessness, hopelessness, guilt, and suicidal ideation due to baseline cognitive and/or expressive language limitations.**



Depression

Literature Review

- Small case reports
- Selective serotonin reuptake inhibitors and amitriptyline were generally effective; desipramine was ineffective
- In general, there is evidence of sub-optimal treatment of depression in DS
- Treatment has usually been limited to one drug with no alternative drug prescribed when the first one failed
- 1 retrospective study of SSRIs

No randomized controlled trials of antidepressants in DS

Walker JC et al. (2011). Res Dev Disabil 32:1432-1440



Depression (Cont'd)

12-week retrospective study

SSRIs (fluoxetine (8), sertraline (2), escitalopram (1))

11 adults with DS (ages 18-46; 7 male:4 female)

Responders = CGI-I of much or very much improved

82% (9/11) responded to treatment with a SSRI

36% (4/11) experienced at least 1 side effect; anger and daytimes sedation most common

Thom, R. P. et al. (2021). *Brain sciences*, 11(9), 1216



Dementia

- **Symptoms can start around age 40 years**
- **77% of adults with DS age 60-69 years; 100% will display cognitive decline by age 70 years**
- **Initial symptoms**
 - **Initial decline in episodic memory, attention, and executive functioning**
 - **Decline in visuospatial ability, verbal fluency, motor coordination and planning follows**
- **Screening for dementia is advised to start at age 40 years**
- **Currently, there are no approved drugs for treating dementia in persons with DS**
- **Cochrane review 2015 - insufficient evidence exists as to whether medications approved for treating sporadic Alzheimer's dementia are effective in treating cognitive decline in persons with DS**

Fortea, SJH, et al. *Lancet Neurol.* 2021 Nov;20(11):930–42.



Dementia vs Depression

- **Depression more likely in younger adults with DS**
- **Depressive symptoms accompany or precede the cognitive decline**
- **For cases that are unclear, treatment for depression is relatively low risk in a healthy adult with DS**



Research Opportunity



MGH Lurie Center treatment research study for depression in adults with Down syndrome



Clinical Trial of Fluoxetine (Prozac)

- Study Goal: to understand whether fluoxetine (Prozac) is effective for depression in people with Down syndrome

We are looking for participants who are...

- 18-45 years old with Down syndrome
- Have symptoms of depression (e.g., loss of interest in activities, less social, loss of verbal skills, crying, change in appetite)



What can you expect in the study



- First visit in person at the Lurie Center in Lexington MA to confirm diagnosis of depression with MD and prescribe Fluoxetine (Prozac) if medically appropriate
- Brief, biweekly follow up visits over 4 months on Zoom/telephone

Screen and Baseline
visit: 3 hours in person

Weeks 2, 6, and 10:
30-minute phone call

Weeks 4, 8, 12, and
16: 1.5 hours via zoom



Why might you consider this opportunity?



- To be evaluated for depression by a psychiatrist who specializes in Down syndrome and neurodevelopmental differences and if appropriate start medication treatment without joining a long waitlist
- Far more monitoring than one would receive if they were prescribed the medication in regular clinical practice
- Only payment on participant is co-pay for medication from the pharmacy no payments for visits with study psychiatrist



How to get in touch about this research opportunity

Laura Sarnie

- Research Coordinator for the study
- lsarnie@mgh.harvard.edu
- 781-860-1764

Lurie Center Research Office

- General research office information where someone will connect you with study staff
- luricenterresearch@partners.org
- 781-860-1711

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Questions?

