

Appendix C. PCP Plan



09/27/2017

Dear Dr. Schwartz,

The caregiver of your patient, **Allison Hanselman (DOB 08/20/1980)**, is participating in a research project aimed at improving healthcare outcomes for patients with Down syndrome. The project is coordinated by a team of clinicians and researchers at Massachusetts General Hospital in Boston and is funded by a grant from the Patient-Centered Outcomes Research Institute. More information about our project can be found at www.downsyndromeclinictoyou.com.

The caregiver of your patient completed an online questionnaire which generated automated suggestions for testing and treatment that are anchored on published practice guidelines and/or expert consensus. The online tool encouraged **Allison's** caregiver to share and discuss these with you.

On the next page, you will find a checklist of these recommendations and list of educational resources specific for Down syndrome. We hope you will find them helpful during your next clinical visit with this patient.

Sincerely,

MGH Down Syndrome Program Research Team

P.S. As we are testing the efficacy of this intervention alone, we are not available for clinical consultation by phone or e-mail. If you have any technical questions, however, regarding the accessibility of this study's resources, please e-mail dsc2u@mgh.harvard.edu.

Personalized Checklist for Allison's Provider

The caregiver of your patient completed an online questionnaire which generated automated suggestions for testing and treatment that are anchored on published practice guidelines and/or expert consensus.

This checklist does not establish a health care provider-patient relationship. It is not an attempt to practice medicine or provide specific clinical advice. It is intended to provide useful information to you for reference and educational purposes only. It contains auto-programmed suggestions based on answers provided by your patient's caregiver to the Down Syndrome Clinic to You (DSC2U) survey and on national guidelines. It was not prepared or reviewed by a clinician specifically for your patient. The content of this letter is not meant to be complete or exhaustive or to be a substitute for professional medical advice, diagnosis or treatment. You are responsible for exercising independent judgment about the contents of this letter and for recommending and implementing any care or other course of action for your patient.

You might choose to check each item when completed for Allison.

Recommended Labs, Tests, and Procedures for Allison

(AAP = American Academy of Pediatrics)

- Dental visit.** Allison's caregiver indicated that Allison has not had a dental exam within the past 6 months.
- Flu shot.** The same precautions and contraindications for the general population apply to people with Down syndrome. Allison's caregiver indicated that Allison gets a flu shot "most years."
- Pneumococcal vaccine.** Experts specializing in Down syndrome recommend that adults with Down syndrome receive PPSV23 once at age 21, again at age 25, and again at age 50. This is due to the lower overall immunity in people with Down syndrome. Allison's caregiver indicated that Allison has not received a pneumococcal vaccine.
- SLP and Neuropsych referral.** Allison's caregiver indicated that Allison has experienced a change in her ability to speak, and indicated that there has been a decrease in Allison's speaking clarity or fluency and Allison is speaking less now. An SLP and neuropsychologist may help determine why these changes have happened.

Potential New Conditions/Diagnoses to be Considered for Allison

We recommend that you consider initiating evaluations for the following conditions that can often co-occur with Down syndrome:

- Obsessive-Compulsive Disorder (OCD).** Allison's caregiver marked that within the past 6 months of completing our intake, Allison experienced ritualistic compulsive behaviors and that Allison finds these distressing, or they disrupt her daily routine. OCD is a common co-occurring condition for people with Down syndrome. Resources and book recommendations are on our web page. Psychopharmacological consult should be considered if possible underlying medical causes are treated and eliminated.
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Arthropathies. Allison's caregiver indicated that within the past month of completing our intake, Allison has experienced joint stiffness, joint swelling, joint pain. Gout and osteoarthritis are all common in people with Down syndrome, and a full standard work up should be pursued in patients presenting with symptoms of joint pathology, including a workup for other connective tissue disorders.

- Atopic dermatitis.** Allison's caregiver indicated that within the past month of completing our intake, Allison has experienced eczema. This may be suggestive of eczema, which can be common in people with Down syndrome. Pursue the same treatment options that you would use in the typically developing population.
 - Hidradenitis suppurativa.** Allison's caregiver indicated that within the past month of completing our intake, Allison has experienced skin boils under armpits and groins. The full range of skin boils (folliculitis, furuncles, carbuncles, and hidradenitis suppurativa) have an increased incidence in people with Down syndrome. Consider a dermatology referral, if needed.
 - Acne.** Allison's caregiver indicated that acne is one of their current medical concerns for Allison. Consider discussing different treatment options and pursuing a dermatology referral, if necessary. Treatment options are the same for persons with Down syndrome.
 - Menstrual complaints.** Allison's caregiver indicated that within the past month of completing our intake Allison has experienced irregular periods and severe cramps. Menstrual complaints such as primary dysmenorrhea and metorrhagia can occur in women and girls with Down syndrome, although indicators of menstrual pain may be more subtle (for example, reduction in activity levels, changes in behavior while menstruating, etc.). Treatment is the same as in the general population, although it is worth considering that OCP use **may** carry a slightly increased risk of thromboembolism in women with Down syndrome.
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OTHER INFORMATION, RESOURCES, and SUPPORTS for Allison

For your information, we provided Allison's caregiver links to the following online resources and information. If you would like online access to these resources, please go to [!!!!URL to be inserted!!!!](mailto:URL to be inserted).

Health and Wellness Resources

- Disruptive behaviors
 - Dating and Social Boundaries
 - Puberty and Sexual Development
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Nutrition

- Allison should be encouraged to increase her overall calcium intake.
 - Allison should be encouraged to develop healthier snacking habits.
 - Resources for healthy eating habits in persons with Down syndrome.
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Life Skills

- Allison's caregiver would like for Allison to learn how to ask questions of her doctors.
- Allison's caregiver would like for Allison to learn how to describe how she is feeling to her doctor.
- Allison's caregiver would like for Allison to learn how to take her medications every day on her own.
- Allison's caregiver would like for Allison to learn how to call 911 if there is an emergency.
- Allison's caregiver would like for Allison to learn how to provide her personal information when needed.
- Allison's caregiver would like for Allison to learn how to tell the difference between a stranger and a friend.
- Allison's caregiver would like for Allison to learn how to do household chores.
- Allison's caregiver would like for Allison to be able to bathe/shower her self.
- Allison's caregiver would like for Allison to learn what each medication is for.
- Allison's caregiver would like for Allison to learn how to refill her prescriptions on her own.
- Allison's caregiver would like for Allison to learn about the differences between healthy and unhealthy foods.
- Allison's caregiver would like for Allison to learn how to use public transportation on her own.
- Allison's caregiver would like for Allison to prepare her own meals.

- Allison's caregiver would like for Allison to have a plan for what she will do after finishing high school.
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Education

- Adaptive living skills
 - Vocational skill/employment opportunities
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Caregiver Information

- The Arc organization
- DS-Connect® Down syndrome registry
- LuMind Research Down Syndrome Foundation
- We provided a link to access a list of all the Down syndrome organizations in the different states in the USA
- We provided resources on setting up a special needs trusts or an ABLE account
- Supports for brothers and sisters
- Resources for moving out/residential options for people with Down syndrome