



08/04/2020

Dear Dr. Ryan,

The caregiver of your patient, **Alison Smith (DOB 08/04/2004)**, completed an online healthcare tool developed by a team of researchers at Massachusetts General Hospital in Boston. For more information about this tool, called Down Syndrome Clinic to You (DSC2U), please visit <https://www.dsc2u.org>.

DSC2U generates automated suggestions for testing and treatment that are anchored on published practice guidelines and/or expert consensus. Alison 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.

With every best wish,

The DSC2U team

## Personalized Checklist for Alison'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 Alison.

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### Recommended Labs, Tests, and Procedures for Alison

*(AAP = American Academy of Pediatrics)*

- Audiogram/hearing test.** For ages 1 to 21, AAP recommends annual audiograms given increased incidence of hearing loss in this population.
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**Ophthalmology Evaluation:** AAP recommends an ophthalmologic exam at least every three years for people with Down syndrome, ages 13 and 21.

- Sleep study.** Alison's caregiver indicated that Alison has never had a sleep study. The AAP recommends that all children with Down syndrome be screened for obstructive sleep apnea by undergoing a sleep study by age four, even in the absence of symptoms, and then further sleep studies later in life if symptoms arise. The prevalence of obstructive sleep apnea in patients with Down syndrome is reported to be up to 75%. Research has also shown that patients with Down syndrome may lose up to 9 IQ points within a year when their apnea is untreated.
- Thyroid function tests (TSH & fT4).** Alison's caregiver indicated that within the past 12 months of completing our intake, they are unsure whether or not Alison has had her thyroid levels drawn. The American Academy of Pediatrics recommends that everyone with Down syndrome have their thyroid levels checked once annually, given the high incidence of thyroid disorders in patients with Down syndrome.
- Hemoglobin level.** Alison's caregiver indicated that they are not sure if Alison has had a hemoglobin level performed within the past 12 months. The AAP recommends that everyone with Down syndrome have a hemoglobin level checked annually to assess for iron-deficiency anemia. If Hg < 11, the AAP recommends one of these follow-up labs: (1) ferritin and CRP or (2) reticulocyte hemoglobin (CHr). If (1) CRP is normal and ferritin is low or (2) CHr is low, then iron augmentation through diet or supplements is recommended.
- Dental visit.** Alison's caregiver indicated that they were unsure if Alison had a dental exam within the past 6 months.
- Flu shot.** [More information on vaccines and Down syndrome.](#) [↗](#) The same precautions and contraindications for the general population apply to people with Down syndrome. Alison's caregiver indicated that Alison gets a flu shot "some years."
- HPV vaccine.** Experts specializing in Down syndrome recommend that people with Down syndrome between the ages of 9 and 26 receive the standard doses of the human papillomavirus vaccine (HPV) as in the general population. Alison's caregiver indicated that Alison has not received the HPV vaccine.

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## Potential New Conditions/Diagnoses to be Considered for Alison

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

- Obsessive-Compulsive Disorder (OCD).** Alison's caregiver marked that within the past 6 months of completing our intake, Alison experienced ritualistic compulsive behaviors and that Alison 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.
- Dry Skin/Xerosis.** Alison's caregiver indicated that within the past month of completing our intake, Alison has experienced dry skin. This may be suggestive of xerosis, which can be common in people with Down syndrome. Pursue the same treatment options that you would use in the typically developing population.
- Acne.** Alison's caregiver indicated that acne is one of their current medical concerns for Alison. Consider discussing different treatment options and pursuing a dermatology

referral, if necessary. Treatment options are the same for persons with Down syndrome.

- Seasonal allergies.** Alison's caregiver indicated that within the past month of completing our intake, seasonal allergies was one of their current medical concerns for Alison. We recommended discussing with you some medications to help alleviate some of these symptoms.
- Menstrual complaints.** Alison's caregiver indicated that within the past month of completing our intake Alison has experienced irregular periods. Menstrual complaints such as primary dysmenorrhea and metrorrhagia 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.

## OTHER INFORMATION, RESOURCES, and SUPPORTS for Alison

For your information, we provided Alison's caregiver links to the following online resources and information. If you would like online access to these resources, please go to <https://www.dsc2u.org/primarycare>.

### Health and Wellness Resources

- Puberty and Sexual Development
- Resources on possible eligibility for the Supplemental Nutrition Assistance Program, and tips on eating on a budget

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### Nutrition

- Alison should be encouraged to increase her overall calcium intake.
- Alison should increase her dietary intake of fruit and vegetables.
- Resources for healthy eating habits in children with Down syndrome.

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### Life Skills

- Alison's caregiver would like for Alison to learn how to ask questions of her doctors.
- Alison's caregiver would like for Alison to learn how to describe how she is feeling to her doctor.
- Alison's caregiver would like for Alison to learn what each medication is for.
- Alison's caregiver would like for Alison to learn how to take her medications every day on her own.
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Alison's caregiver would like for Alison to learn how to refill her prescriptions on her own.

- Alison's caregiver would like for Alison to learn about the differences between healthy and unhealthy foods.
- Alison's caregiver would like for Alison to learn how to call 911 if there is an emergency.
- Alison's caregiver would like for Alison to exercise regularly.
- Alison's caregiver would like for Alison to learn how to provide her personal information when needed.
- Alison's caregiver would like for Alison to learn how to tell the difference between a stranger and a friend.
- Alison's caregiver would like for Alison to learn how to use public transportation on her own.
- Alison's caregiver would like for Alison to learn how to do household chores.
- Alison's caregiver would like for Alison to understand sexual boundaries and privacy.
- Alison's caregiver would like for Alison to learn how to brush her teeth on her own.
- Alison's caregiver would like for Alison to have a plan for what she will do after finishing high school.
- Alison's caregiver would like for Alison to prepare her own meals.

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## Education

- Math skills

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## Caregiver Information

- Best Buddies organization
- GiGi's Playhouse
- 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
- Alison's caregiver requested information on Alison's genetic diagnosis