An online personal care plan for caregivers and primary care physicians

DSC2U
Down Syndrome Clinic to You

Alexa Gozdiff Spognardi, MS, MPH

Massachusetts General Hospital
Founding Member, Mass General Brigham

HARVARD
MEDICAL SCHOOL

Quick Poll:

What is the age of your loved one with Down syndrome?

Do not edit
How to change the design

Join at slido.com
#1995798

Presenting with animations, GIFs or speaker notes? Enable our Chrome extension

slido

Do not edit

How to change the design

What is the age of your loved one with Down syndrome?

Quick Poll:

Do you feel your loved one's primary care provider is knowledgeable about Down syndrome specialty care?

Do you feel your loved one's primary care provider is knowledgeable about specialty care for Down syndrome?

Quick Poll:

Within the past three years has your loved one visited a Down syndrome specialty clinic?

Do not edit

How to change the design

Within the past 3 years has your loved one with Down syndrome gone to a Down syndrome specialty clinic?

This is a personal mission for us.

- Lexie has an uncle with Down syndrome.
- He is 65 years old.
- Rob lives in Massachusetts and has never participated in a DS specialty clinic.

- Brian has a sister with Down syndrome.
- She is 44 years old.
- There are no adult Down syndrome clinics in Cleveland, where she lives with their parents.

01. THE NEED

Most people with Down syndrome don't have access to specialized medical care.

02. PART OF THE SOLUTION

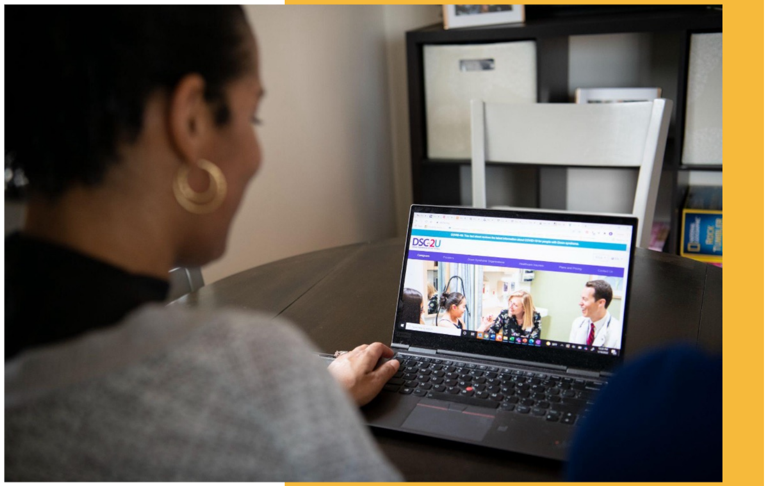
DSC2U offers expert, personalized health guidance—anytime, anywhere.

03. THE IMPACT

Families are catching missed issues and advocating with confidence.

04. CALL TO ACTION

You can help others access this life-changing resource.



DSC2U
Down Syndrome Clinic to You

01

THE NEED

Most people with Down syndrome don’t have access to specialized medical care.

Parents who have children with Down syndrome worry the medical establishment has passed them by.

Patricia E. Bauer
Mother

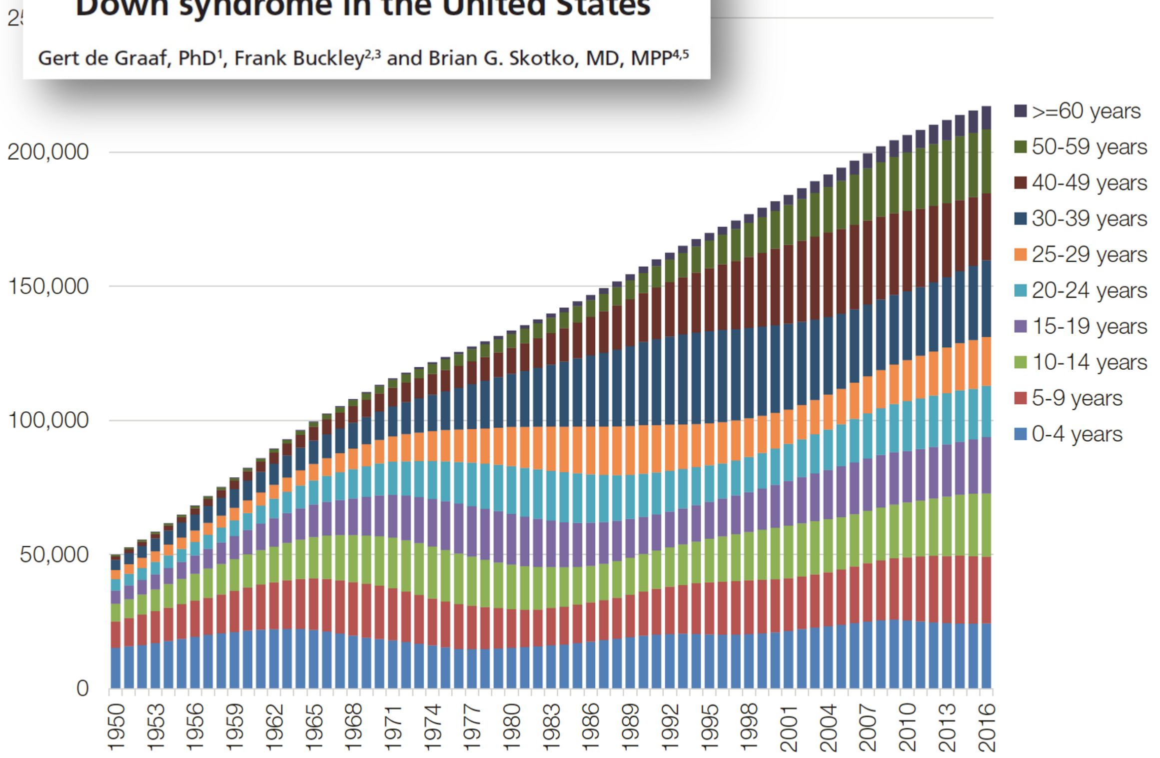
"In an era when the offer of prenatal testing is universal and termination of pregnancies involving Down syndrome is commonplace, families of people with Down syndrome often say ***they worry that the medical establishment has passed them by****. They feel marginalized, unseen, and unserved. Families of people with Down syndrome don't want admiration, and they don't want pity.* ***They feel a critical and urgent need for adequate health care for their loved ones, which is the right of every American.****"*

—Patricia Bauer, caregiver

217,000 with Down syndrome in the U.S
~4 million people worldwide

Estimation of the number of people with Down syndrome in the United States

Gert de Graaf, PhD[1], Frank Buckley[2,3] and Brian G. Skotko, MD, MPP[4,5]



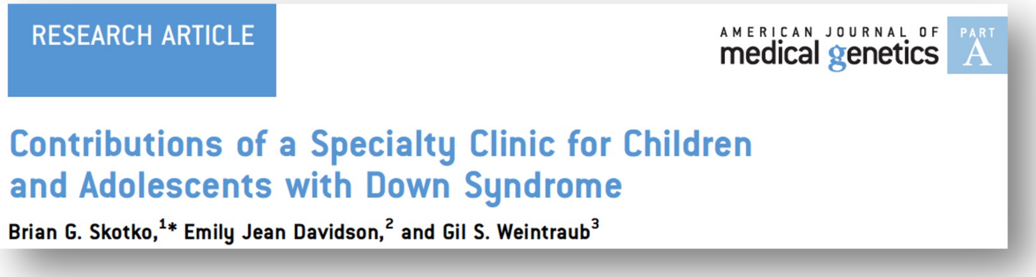
www.ndss.org/Resources/Health-Care

There are 71 Down syndrome clinics in U.S.

At best, all of these clinics serve **< 5% of the population** with Down syndrome.

It is unreasonable & impractical for primary care physicians to stay up-to-date on Down syndrome medical care.

<10% of patients with Down syndrome were up-to-date on 5 of the basic healthcare screens recommended by the American Academy of Pediatrics, according to our study



RESEARCH ARTICLE

AMERICAN JOURNAL OF medical genetics PART A

Contributions of a Specialty Clinic for Children and Adolescents with Down Syndrome

Brian G. Skotko,[1]* Emily Jean Davidson,[2] and Gil S. Weintraub[3]

DSC2U
Down Syndrome Clinic to You

02

DSC2U: Part of the Solution

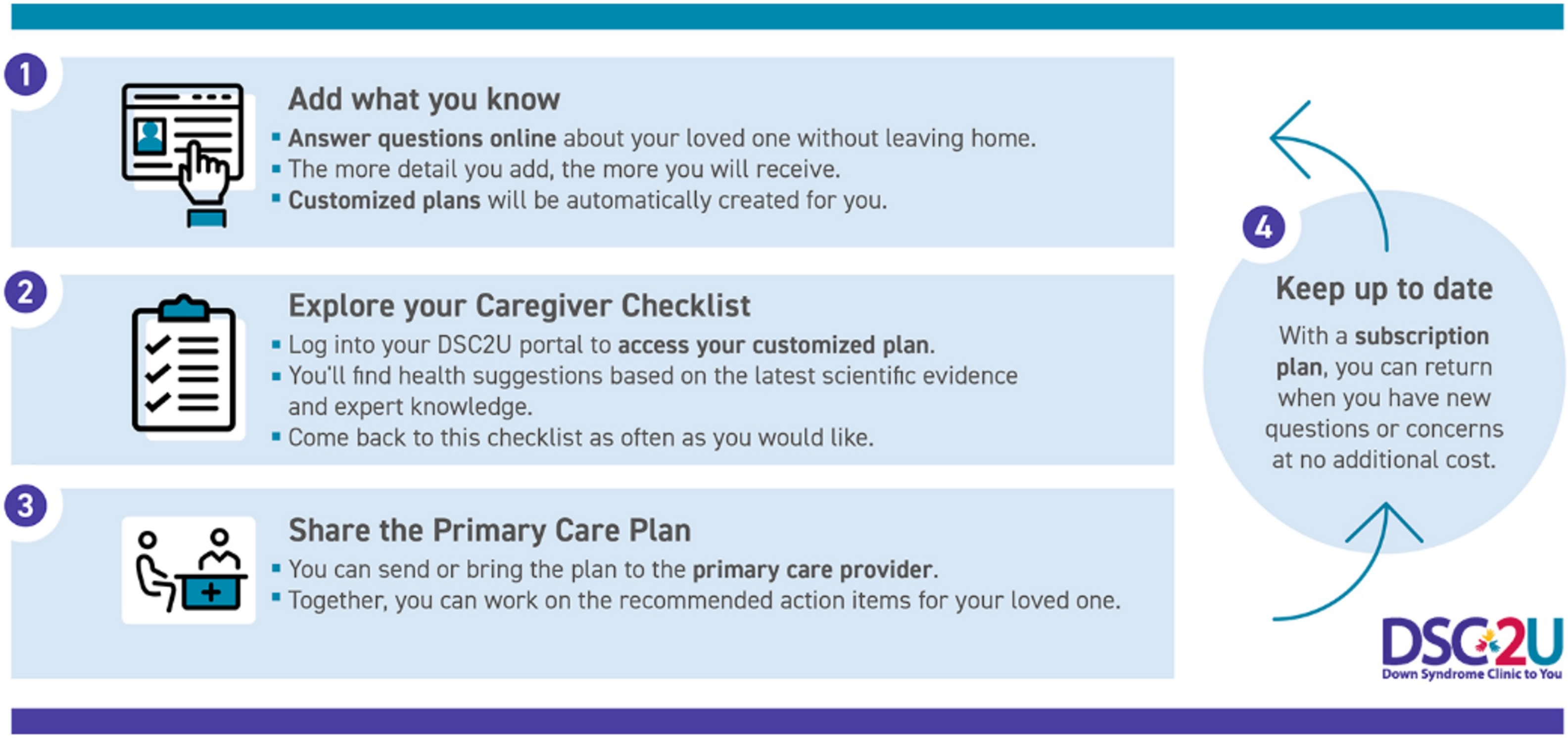
A tool that offers expert, personalized health guidance—anytime, anywhere for all life stages.

DSC2U is an automated, direct-to-consumer tool in English & Spanish

For all life stages after infancy!

Accessible to all families across the globe!

How it works



1

Add what you know

- **Answer questions online** about your loved one without leaving home.
- The more detail you add, the more you will receive.
- **Customized plans** will be automatically created for you.

2

Explore your Caregiver Checklist

- Log into your DSC2U portal to **access your customized plan**.
- You'll find health suggestions based on the latest scientific evidence and expert knowledge.
- Come back to this checklist as often as you would like.

3

Share the Primary Care Plan

- You can send or bring the plan to the **primary care provider**.
- Together, you can work on the recommended action items for your loved one.

4

Keep up to date

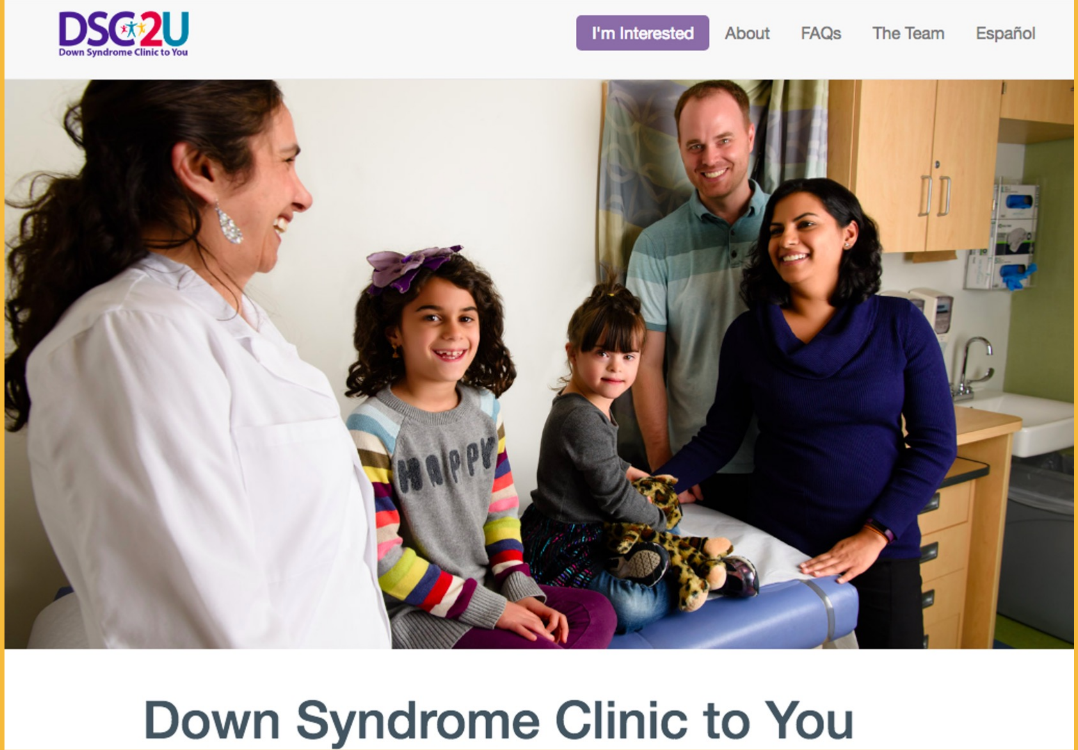
With a **subscription plan**, you can return when you have new questions or concerns at no additional cost.

DSC2U
Down Syndrome Clinic to You

HOW IT STARTED

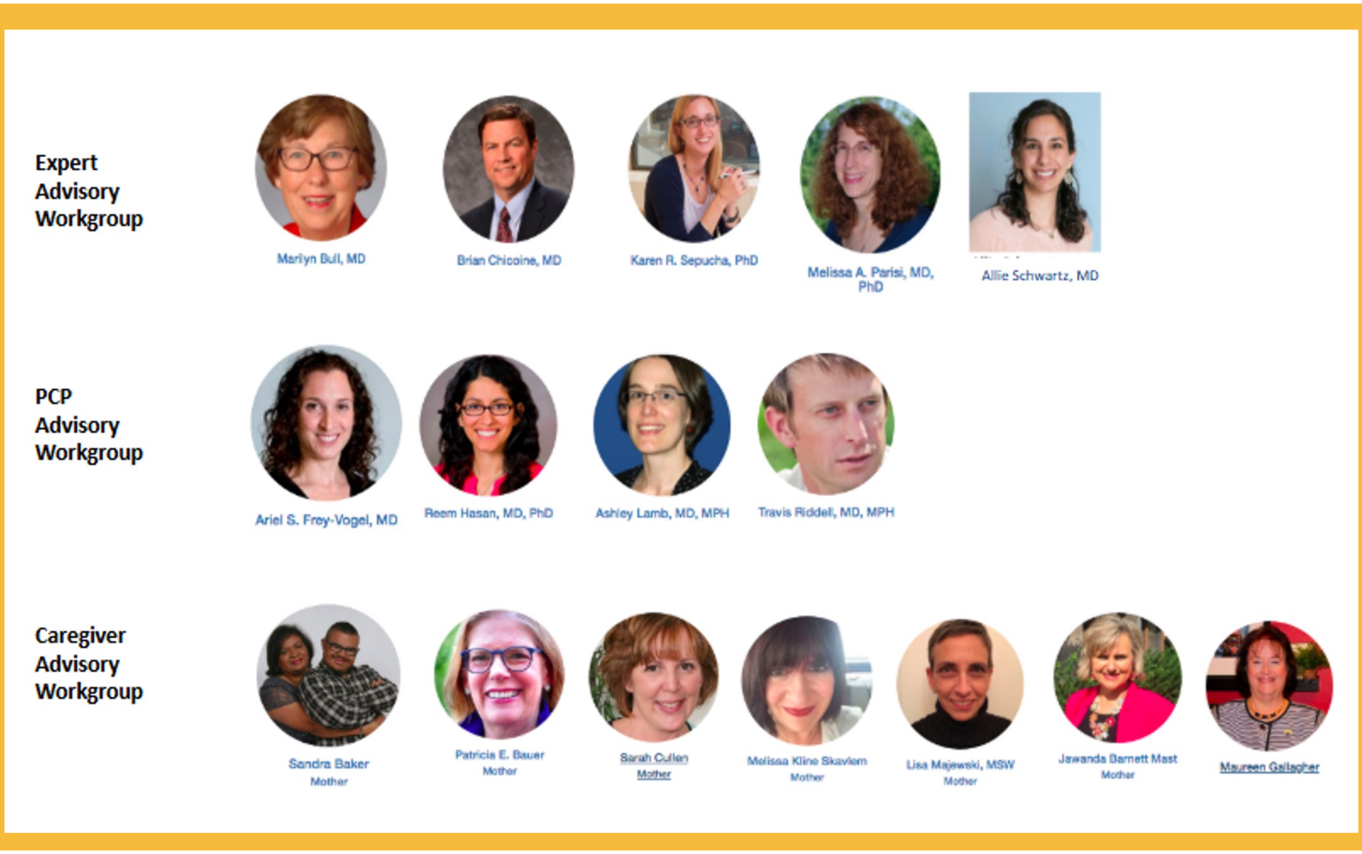
pcori Patient-Centered Outcomes Research Institute

- Initially funded by PCORI
- 3-year, $2.1M project



Down Syndrome Clinic to You

NATIONAL ADVISORY GROUPS



Expert Advisory Workgroup

Marilyn Bull, MD

Brian Chicoine, MD

Karen R. Sepucha, PhD

Melissa A. Parisi, MD, PhD

Allie Schwartz, MD

PCP Advisory Workgroup

Ariel S. Frey-Vogel, MD

Reem Hasan, MD, PhD

Ashley Lamb, MD, MPH

Travis Riddell, MD, MPH

Caregiver Advisory Workgroup

Sandra Baker
Mother

Patricia E. Bauer
Mother

Sarah Cullen
Mother

Melissa Kline Skavlem
Mother

Lisa Majewski, MSW
Mother

Jawanda Barnett Mast
Mother

Maureen Gallagher

OUR MULTIDISCIPLINARY TEAM

MassGeneral Hospital DSC2U Team

DSC2U
Down Syndrome Clinic to You

Program Physicians

Brian Skotko
MD, MPP
Director

Jeanhee Chung
MD, MS
Medical Informatics

Nicolas Oreskovic
MD, MPH

Stephanie Santoro
MD

Administration

Amy Torres
BS
Program Manager

Alexa Spognardi
BS, MS, MPH
Research Assistant

Collaborators

Karen Donelan
ScD, EdM
Survey Researcher

Eric Macklin
PhD
Statistician

MGH LCS

Dyan Blewett

Stephen Lorenz

Grace Hsieh
RN, PhD

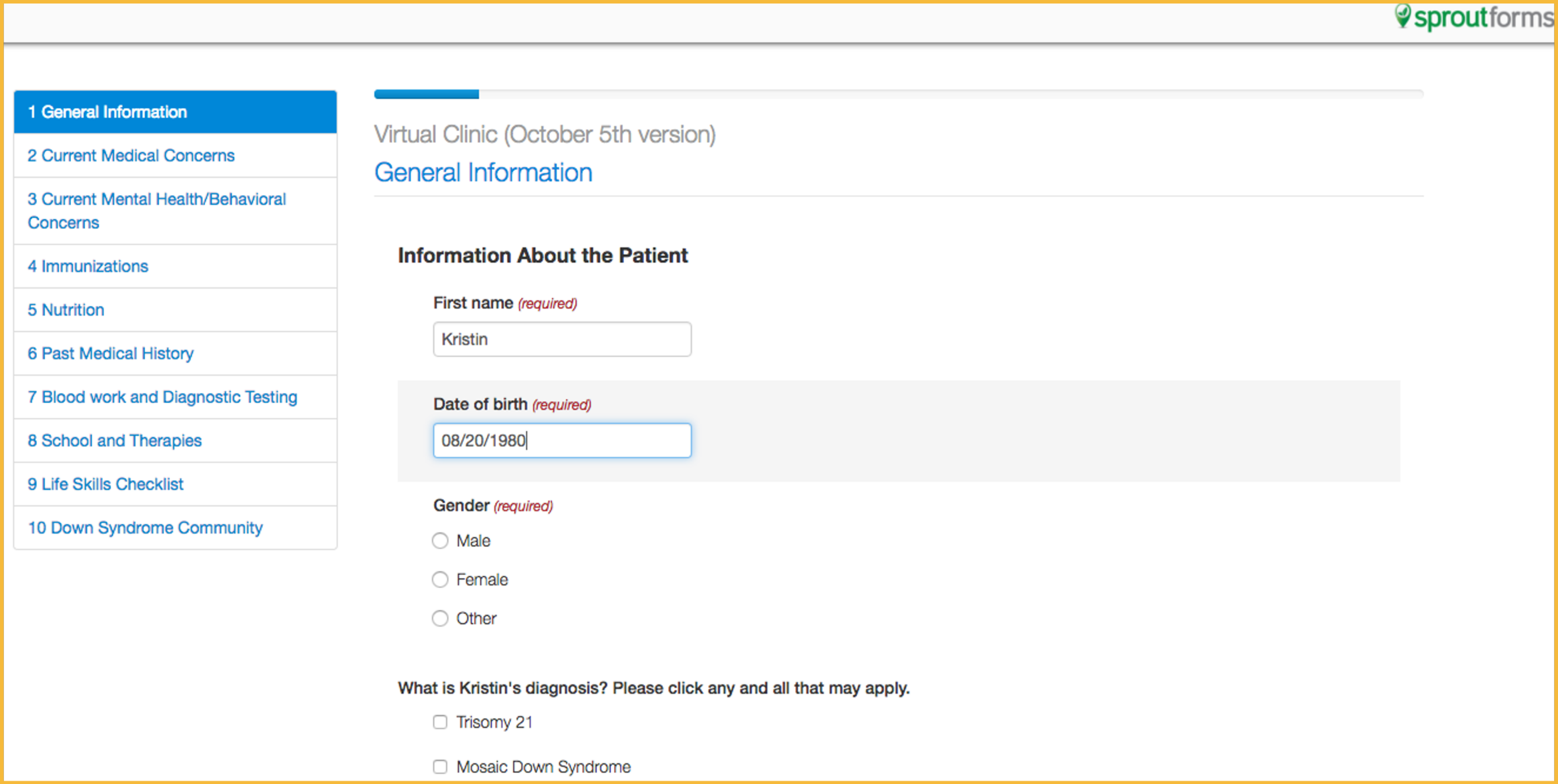
Holy Parker

Mark Wylie

Greg Estey
PhD

Lloyd Clarke

Let’s walk through the form together…



- 1 General Information
- 2 Current Medical Concerns
- 3 Current Mental Health/Behavioral Concerns
- 4 Immunizations
- 5 Nutrition
- 6 Past Medical History
- 7 Blood work and Diagnostic Testing
- 8 School and Therapies
- 9 Life Skills Checklist
- 10 Down Syndrome Community

Virtual Clinic (October 5th version)

General Information

Information About the Patient

First name *(required)*

Kristin

Date of birth *(required)*

08/20/1980

Gender *(required)*

○ Male

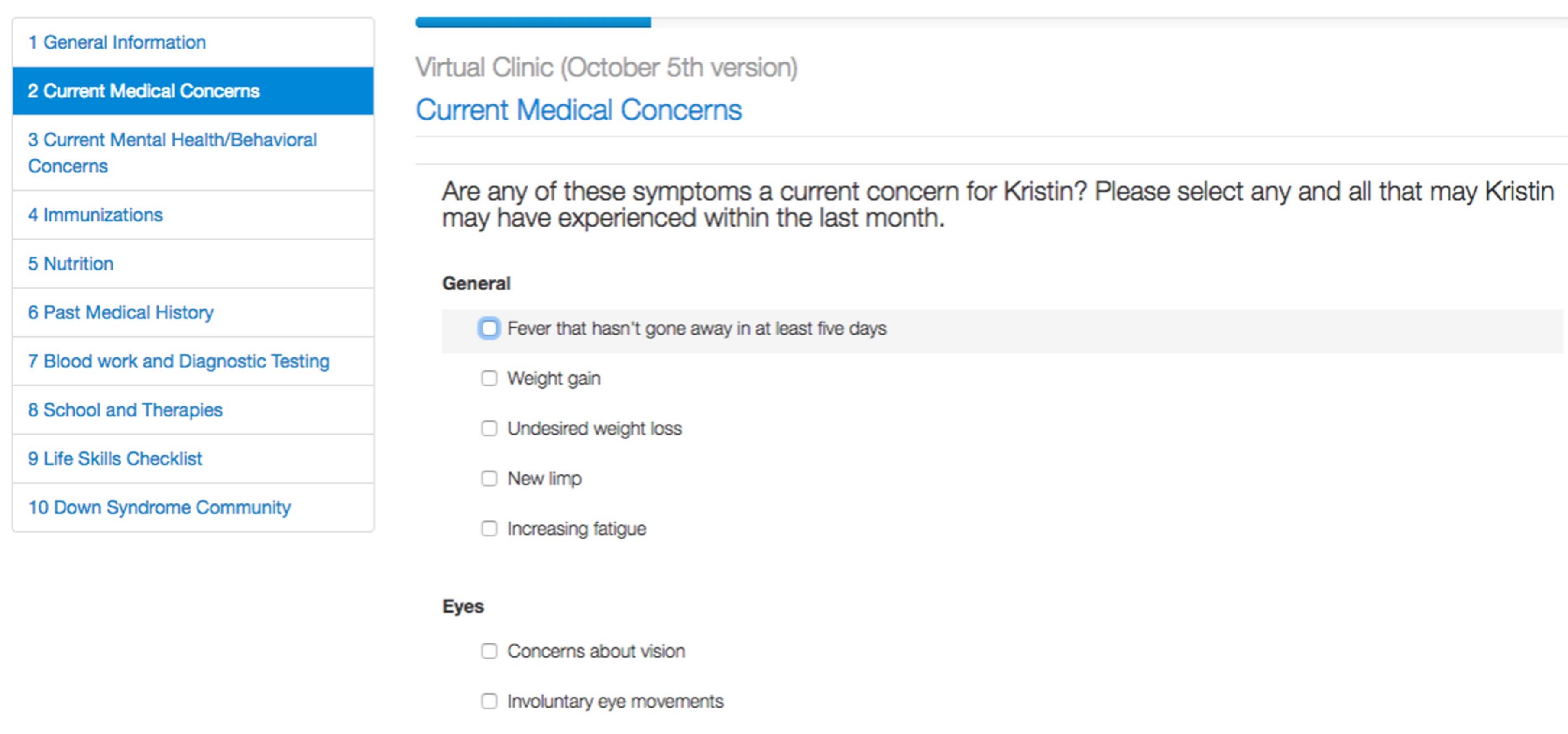
○ Female

○ Other

What is Kristin's diagnosis? Please click any and all that may apply.

☐ Trisomy 21

☐ Mosaic Down Syndrome



- 1 General Information
- **2 Current Medical Concerns**
- 3 Current Mental Health/Behavioral Concerns
- 4 Immunizations
- 5 Nutrition
- 6 Past Medical History
- 7 Blood work and Diagnostic Testing
- 8 School and Therapies
- 9 Life Skills Checklist
- 10 Down Syndrome Community

Virtual Clinic (October 5th version)

Current Medical Concerns

Are any of these symptoms a current concern for Kristin? Please select any and all that may Kristin may have experienced within the last month.

General

☐ Fever that hasn't gone away in at least five days

☐ Weight gain

☐ Undesired weight loss

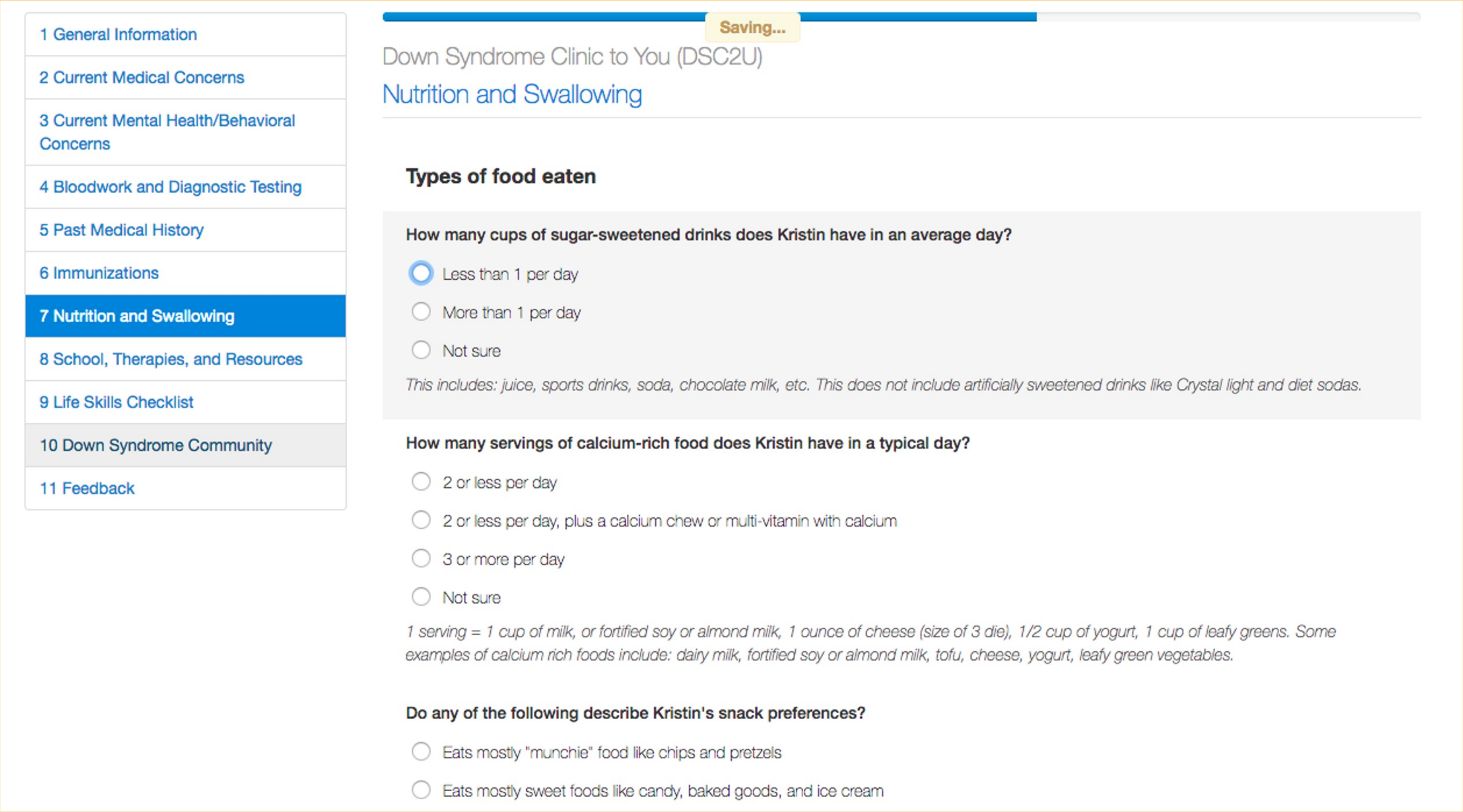
☐ New limp

☐ Increasing fatigue

Eyes

☐ Concerns about vision

☐ Involuntary eye movements



Down Syndrome Clinic to You (DSC2U)

Nutrition and Swallowing

Types of food eaten

How many cups of sugar-sweetened drinks does Kristin have in an average day?

○ Less than 1 per day

○ More than 1 per day

○ Not sure

This includes: juice, sports drinks, soda, chocolate milk, etc. This does not include artificially sweetened drinks like Crystal light and diet sodas.

How many servings of calcium-rich food does Kristin have in a typical day?

○ 2 or less per day

○ 2 or less per day, plus a calcium chew or multi-vitamin with calcium

○ 3 or more per day

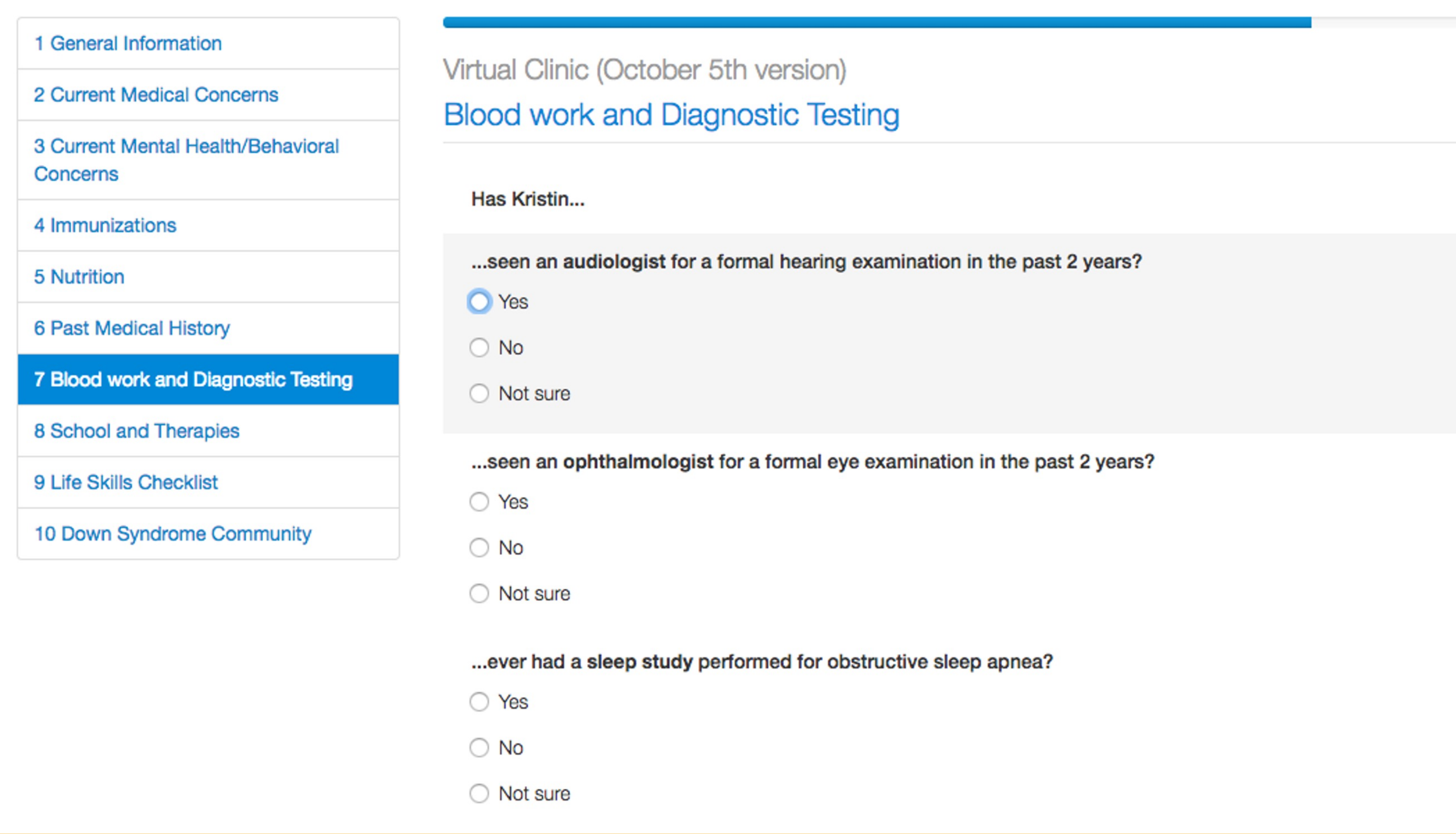
○ Not sure

1 serving = 1 cup of milk, or fortified soy or almond milk, 1 ounce of cheese (size of 3 die), 1/2 cup of yogurt, 1 cup of leafy greens. Some examples of calcium rich foods include: dairy milk, fortified soy or almond milk, tofu, cheese, yogurt, leafy green vegetables.

Do any of the following describe Kristin's snack preferences?

○ Eats mostly "munchie" food like chips and pretzels

○ Eats mostly sweet foods like candy, baked goods, and ice cream



Virtual Clinic (October 5th version)

Blood work and Diagnostic Testing

Has Kristin...

...seen an **audiologist** for a formal hearing examination in the past 2 years?

○ Yes
○ No
○ Not sure

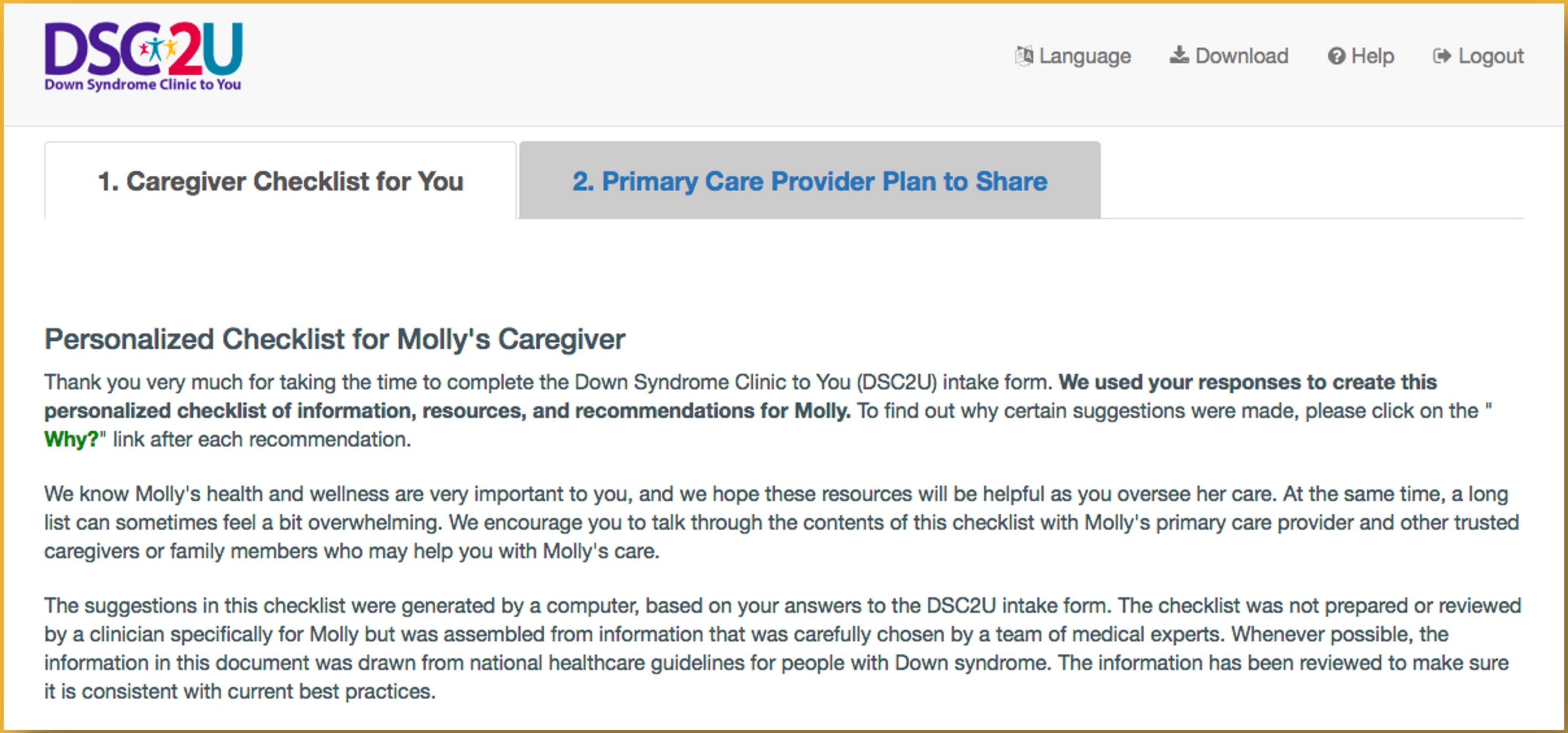
...seen an **ophthalmologist** for a formal eye examination in the past 2 years?

○ Yes
○ No
○ Not sure

...ever had a **sleep study** performed for obstructive sleep apnea?

○ Yes
○ No
○ Not sure

Instantly receive your checklist!

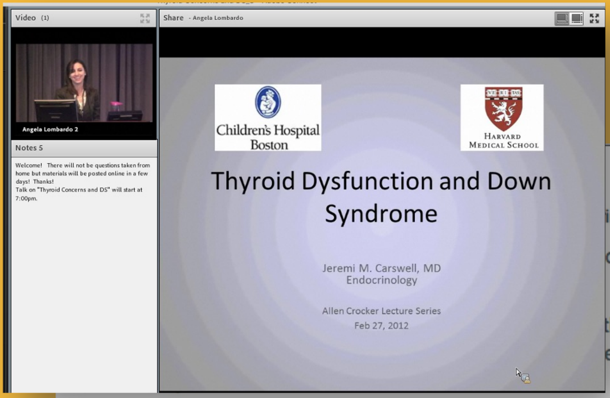


Personalized Checklist for Molly's Caregiver

Thank you very much for taking the time to complete the Down Syndrome Clinic to You (DSC2U) intake form. **We used your responses to create this personalized checklist of information, resources, and recommendations for Molly.** To find out why certain suggestions were made, please click on the " **Why?**" link after each recommendation.

We know Molly's health and wellness are very important to you, and we hope these resources will be helpful as you oversee her care. At the same time, a long list can sometimes feel a bit overwhelming. We encourage you to talk through the contents of this checklist with Molly's primary care provider and other trusted caregivers or family members who may help you with Molly's care.

The suggestions in this checklist were generated by a computer, based on your answers to the DSC2U intake form. The checklist was not prepared or reviewed by a clinician specifically for Molly but was assembled from information that was carefully chosen by a team of medical experts. Whenever possible, the information in this document was drawn from national healthcare guidelines for people with Down syndrome. The information has been reviewed to make sure it is consistent with current best practices.

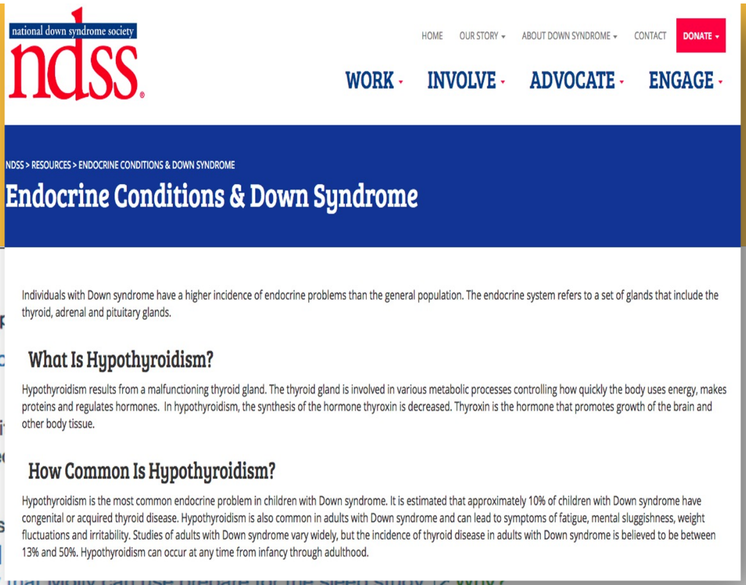


Welcome! There will not be questions taken from home but materials will be posted online in a few days! Thanks!
Talk on "Thyroid Concerns and DS" will start at 7:00pm.

Thyroid Dysfunction and Down Syndrome

Jeremi M. Carswell, MD
Endocrinology

Allen Crocker Lecture Series
Feb 27, 2012



Endocrine Conditions & Down Syndrome

Individuals with Down syndrome have a higher incidence of endocrine problems than the general population. The endocrine system refers to a set of glands that include the thyroid, adrenal and pituitary glands.

What Is Hypothyroidism?

Hypothyroidism results from a malfunctioning thyroid gland. The thyroid gland is involved in various metabolic processes controlling how quickly the body uses energy, makes proteins and regulates hormones. In hypothyroidism, the synthesis of the hormone thyroxin is decreased. Thyroxin is the hormone that promotes growth of the brain and other body tissue.

How Common Is Hypothyroidism?

Hypothyroidism is the most common endocrine problem in children with Down syndrome. It is estimated that approximately 10% of children with Down syndrome have congenital or acquired thyroid disease. Hypothyroidism is also common in adults with Down syndrome and can lead to symptoms of fatigue, mental sluggishness, weight fluctuations and irritability. Studies of adults with Down syndrome vary widely, but the incidence of thyroid disease in adults with Down syndrome is believed to be between 13% and 50%. Hypothyroidism can occur at any time from infancy through adulthood.

ing the following during the up

doctor specialist. More info

that might be consistent wi
e for those with a confirme

☐ **Sleep study.** Molly has symptoms that might be consistent with obstructive s
with many medical consequences if apnea is present and untreated [video]
Here is how caregivers can prepare for sleep studies. Here is a social story that Molly can use prepare for the sleep study. Why?

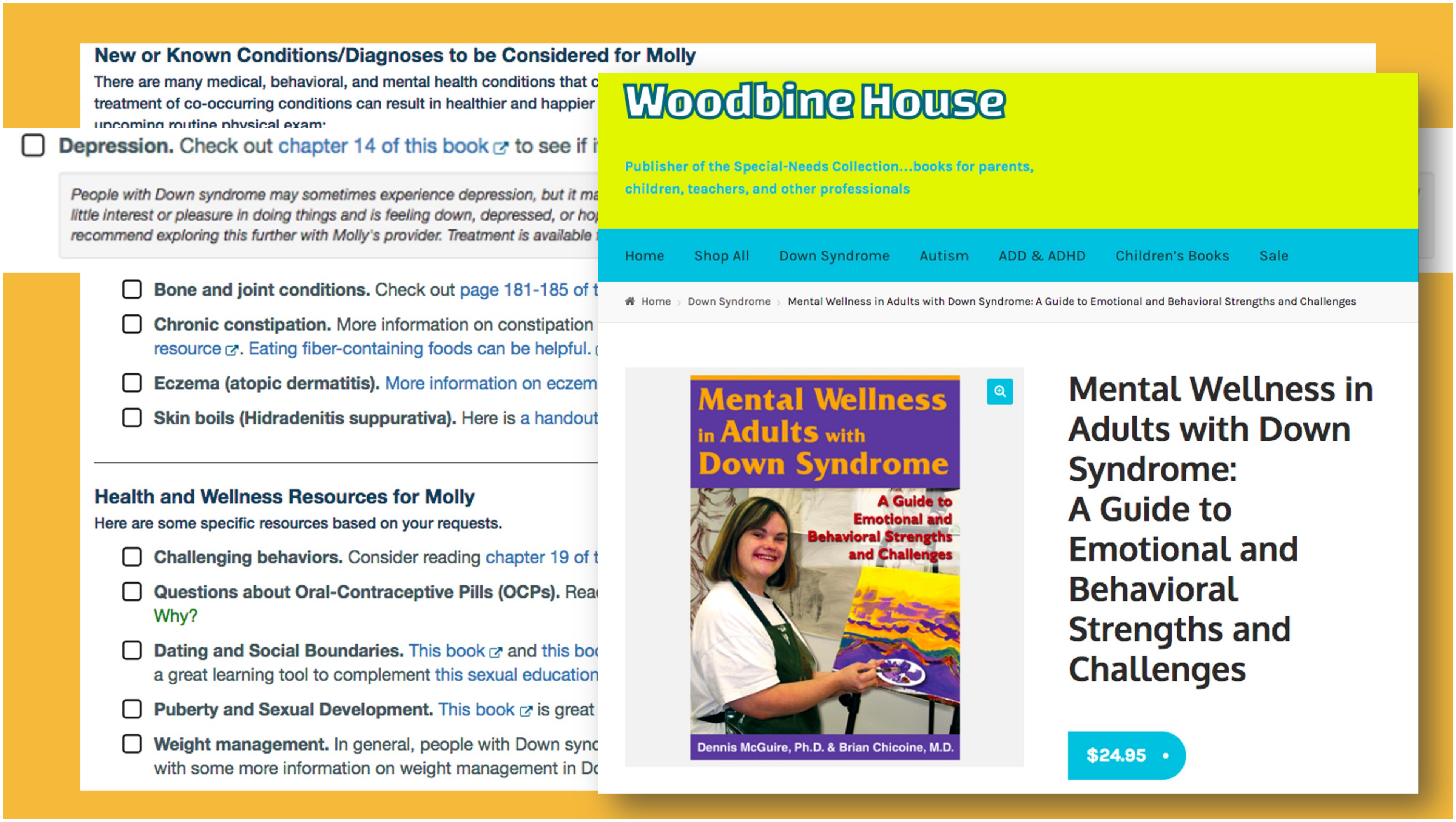
☐ **Thyroid function tests** (blood work). Molly is due for her thyroid check. Further testing is needed. Treatment options are available for those with a confirmed diagnosis [video]. More information on thyroid conditions in Down syndrome. Why?

You indicated that within the past 12 months, Molly has not had her thyroid levels drawn. Individuals with Down syndrome have a significant risk of developing thyroid problems, which are important to treat. Experts recommend that everyone with Down syndrome have thyroid levels checked annually.

☐ **Flu shot.** Why?

☐ **Pneumonia vaccine.** Why?

☐ **SLP and Neuropsych referral.** Talk to Molly's provider about having Molly referred to a Speech and Language Pathologist and a neuropsychologist to assess Molly's speaking abilities. Why?



New or Known Conditions/Diagnoses to be Considered for Molly

There are many medical, behavioral, and mental health conditions that c
treatment of co-occurring conditions can result in healthier and happier
upcoming routine physical exam:

- ☐ **Depression.** Check out chapter 14 of this book to see if i

People with Down syndrome may sometimes experience depression, but it ma little interest or pleasure in doing things and is feeling down, depressed, or hop recommend exploring this further with Molly's provider. Treatment is available

- ☐ **Bone and joint conditions.** Check out page 181-185 of t
- ☐ **Chronic constipation.** More information on constipation resource. Eating fiber-containing foods can be helpful.
- ☐ **Eczema (atopic dermatitis).** More information on eczem
- ☐ **Skin boils (Hidradenitis suppurativa).** Here is a handout

---

Health and Wellness Resources for Molly

Here are some specific resources based on your requests.

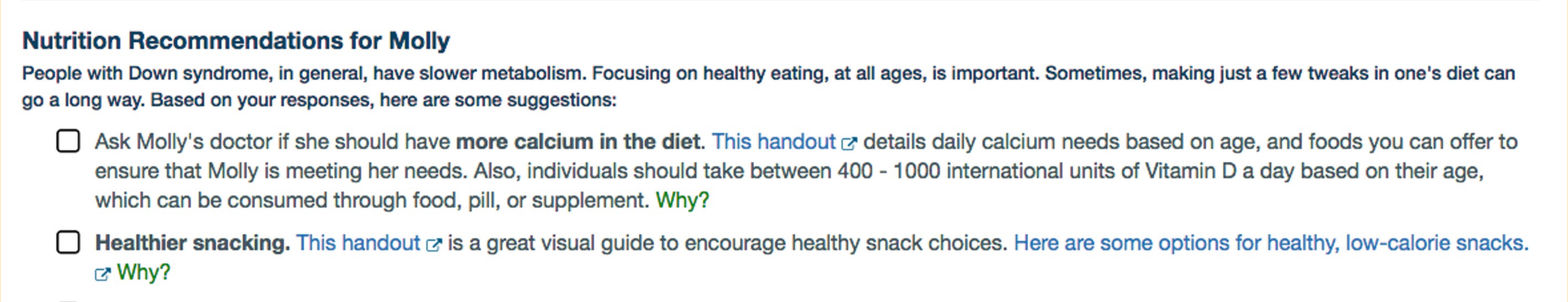
- ☐ **Challenging behaviors.** Consider reading chapter 19 of t
- ☐ **Questions about Oral-Contraceptive Pills (OCPs).** Rea
  Why?
- ☐ **Dating and Social Boundaries.** This book and this boo
  a great learning tool to complement this sexual education
- ☐ **Puberty and Sexual Development.** This book is great
- ☐ **Weight management.** In general, people with Down sync
  with some more information on weight management in Do

Woodbine House

Publisher of the Special-Needs Collection...books for parents, children, teachers, and other professionals

Mental Wellness in Adults with Down Syndrome: A Guide to Emotional and Behavioral Strengths and Challenges

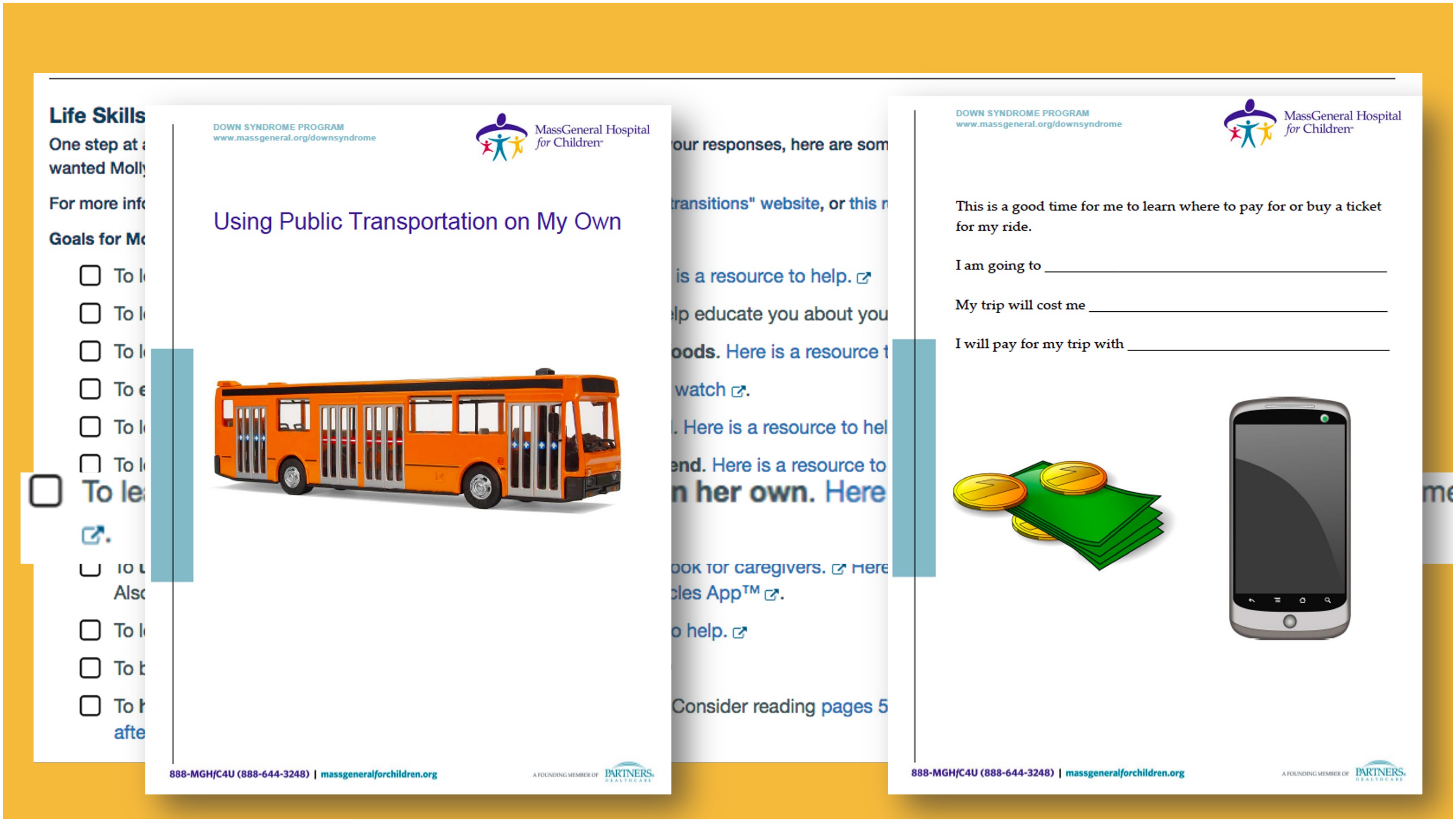
$24.95



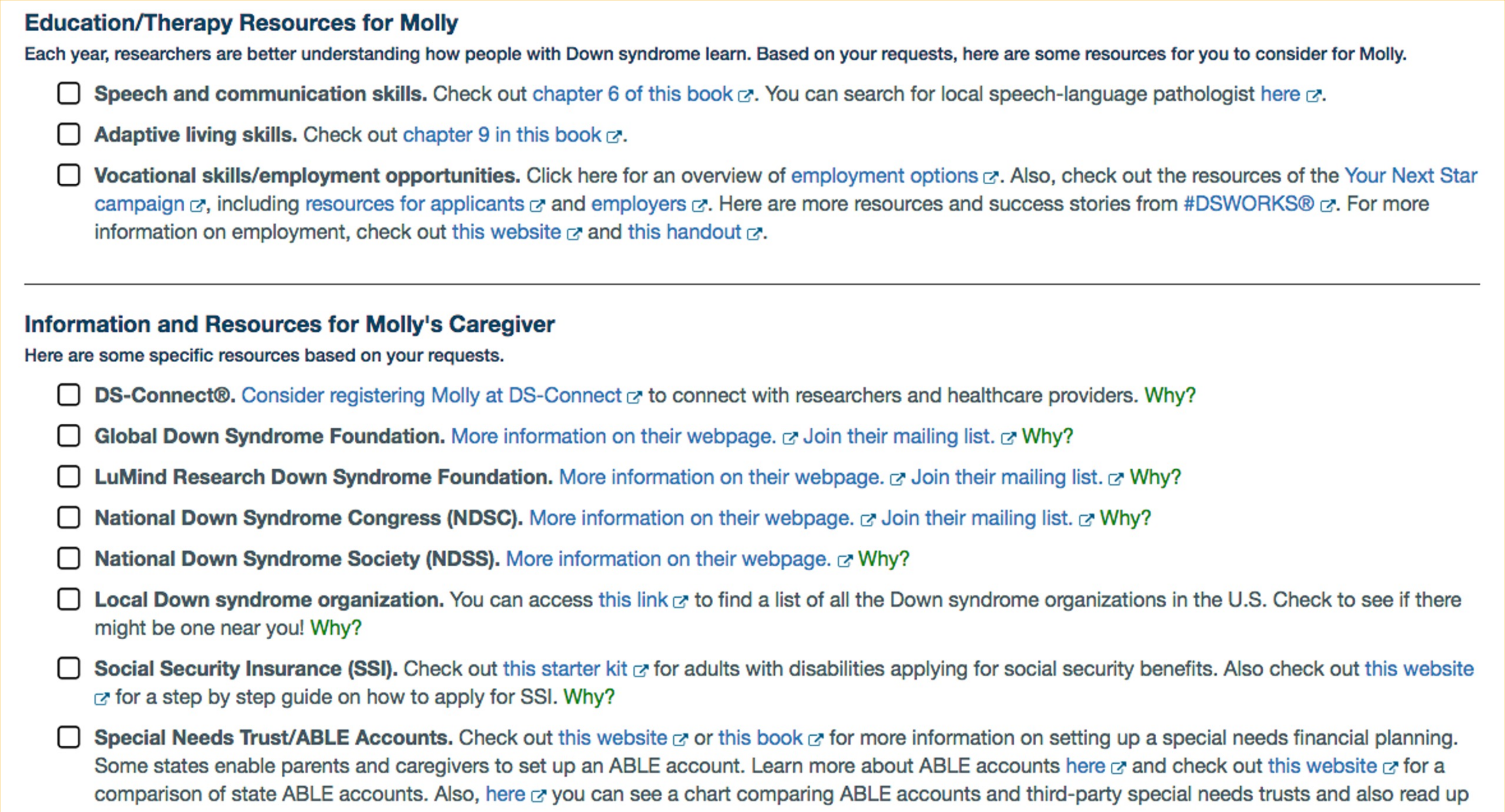
Nutrition Recommendations for Molly

People with Down syndrome, in general, have slower metabolism. Focusing on healthy eating, at all ages, is important. Sometimes, making just a few tweaks in one's diet can go a long way. Based on your responses, here are some suggestions:

- ☐ Ask Molly's doctor if she should have **more calcium in the diet**. This handout ↗ details daily calcium needs based on age, and foods you can offer to ensure that Molly is meeting her needs. Also, individuals should take between 400 - 1000 international units of Vitamin D a day based on their age, which can be consumed through food, pill, or supplement. Why?
- ☐ **Healthier snacking.** This handout ↗ is a great visual guide to encourage healthy snack choices. Here are some options for healthy, low-calorie snacks. ↗ Why?
- ☐ Consider reading this book ↗ for a detailed overview on **healthy nutrition for people with Down syndrome**. Why?



More resources!



Education/Therapy Resources for Molly

Each year, researchers are better understanding how people with Down syndrome learn. Based on your requests, here are some resources for you to consider for Molly.

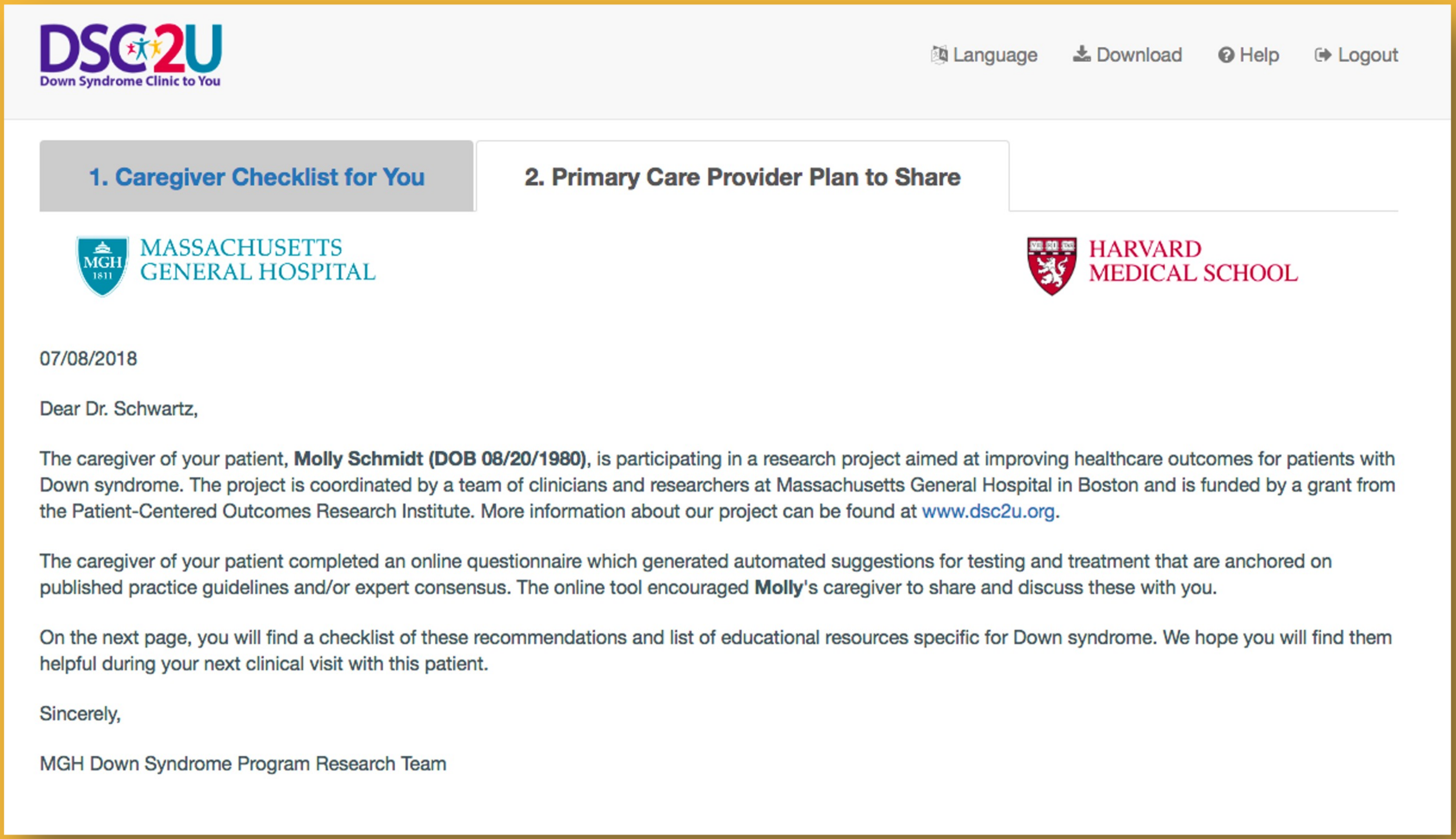
- ☐ **Speech and communication skills.** Check out chapter 6 of this book. You can search for local speech-language pathologist here.
- ☐ **Adaptive living skills.** Check out chapter 9 in this book.
- ☐ **Vocational skills/employment opportunities.** Click here for an overview of employment options. Also, check out the resources of the Your Next Star campaign, including resources for applicants and employers. Here are more resources and success stories from #DSWORKS®. For more information on employment, check out this website and this handout.

Information and Resources for Molly's Caregiver

Here are some specific resources based on your requests.

- ☐ **DS-Connect®.** Consider registering Molly at DS-Connect to connect with researchers and healthcare providers. Why?
- ☐ **Global Down Syndrome Foundation.** More information on their webpage. Join their mailing list. Why?
- ☐ **LuMind Research Down Syndrome Foundation.** More information on their webpage. Join their mailing list. Why?
- ☐ **National Down Syndrome Congress (NDSC).** More information on their webpage. Join their mailing list. Why?
- ☐ **National Down Syndrome Society (NDSS).** More information on their webpage. Why?
- ☐ **Local Down syndrome organization.** You can access this link to find a list of all the Down syndrome organizations in the U.S. Check to see if there might be one near you! Why?
- ☐ **Social Security Insurance (SSI).** Check out this starter kit for adults with disabilities applying for social security benefits. Also check out this website for a step by step guide on how to apply for SSI. Why?
- ☐ **Special Needs Trust/ABLE Accounts.** Check out this website or this book for more information on setting up a special needs financial planning. Some states enable parents and caregivers to set up an ABLE account. Learn more about ABLE accounts here and check out this website for a comparison of state ABLE accounts. Also, here you can see a chart comparing ABLE accounts and third-party special needs trusts and also read up

Don’t forget the PCP Plan



07/08/2018

Dear Dr. Schwartz,

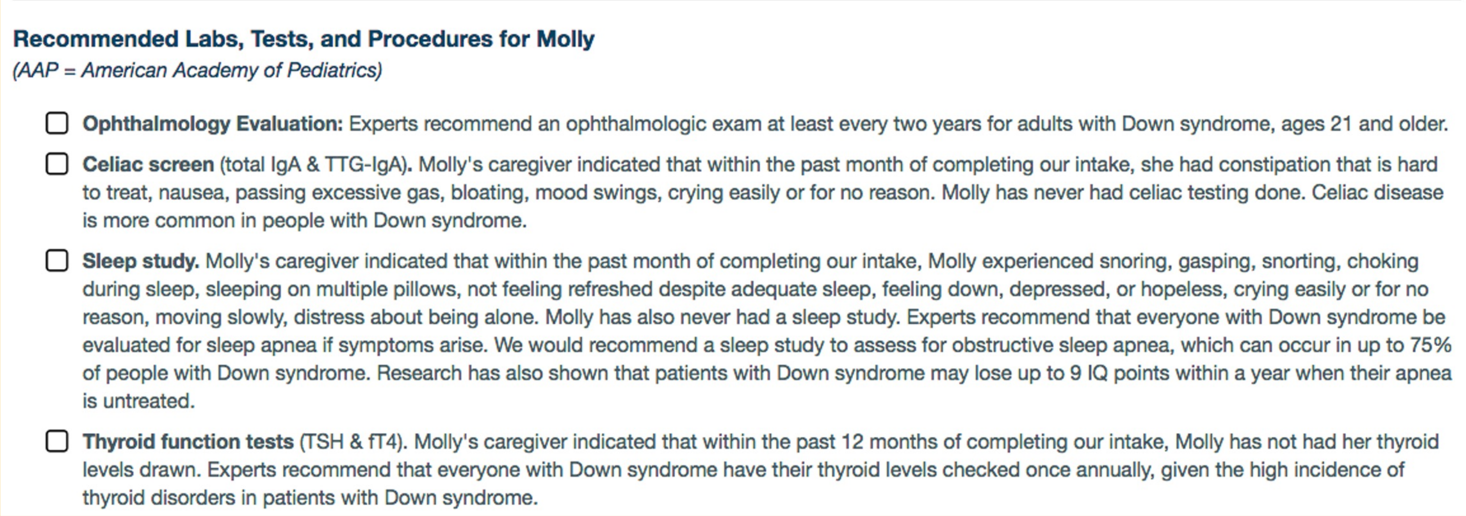
The caregiver of your patient, **Molly Schmidt (DOB 08/20/1980)**, is participating in a research project aimed at improving healthcare outcomes for patients with Down syndrome. The project is coordinated by a team of clinicians and researchers at Massachusetts General Hospital in Boston and is funded by a grant from the Patient-Centered Outcomes Research Institute. More information about our project can be found at www.dsc2u.org.

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 **Molly**'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,

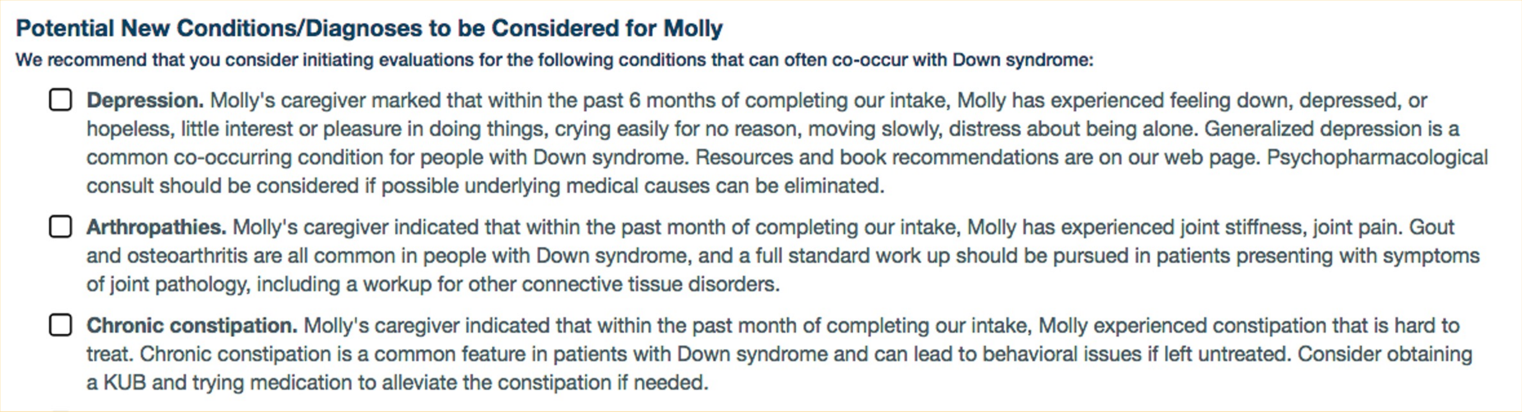
MGH Down Syndrome Program Research Team



Recommended Labs, Tests, and Procedures for Molly

(AAP = American Academy of Pediatrics)

- ☐ **Ophthalmology Evaluation:** Experts recommend an ophthalmologic exam at least every two years for adults with Down syndrome, ages 21 and older.
- ☐ **Celiac screen** (total IgA & TTG-IgA). Molly's caregiver indicated that within the past month of completing our intake, she had constipation that is hard to treat, nausea, passing excessive gas, bloating, mood swings, crying easily or for no reason. Molly has never had celiac testing done. Celiac disease is more common in people with Down syndrome.
- ☐ **Sleep study.** Molly's caregiver indicated that within the past month of completing our intake, Molly experienced snoring, gasping, snorting, choking during sleep, sleeping on multiple pillows, not feeling refreshed despite adequate sleep, feeling down, depressed, or hopeless, crying easily or for no reason, moving slowly, distress about being alone. Molly has also never had a sleep study. Experts recommend that everyone with Down syndrome be evaluated for sleep apnea if symptoms arise. We would recommend a sleep study to assess for obstructive sleep apnea, which can occur in up to 75% of people with Down syndrome. 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). Molly's caregiver indicated that within the past 12 months of completing our intake, Molly has not had her thyroid levels drawn. Experts recommend that everyone with Down syndrome have their thyroid levels checked once annually, given the high incidence of thyroid disorders in patients with Down syndrome.

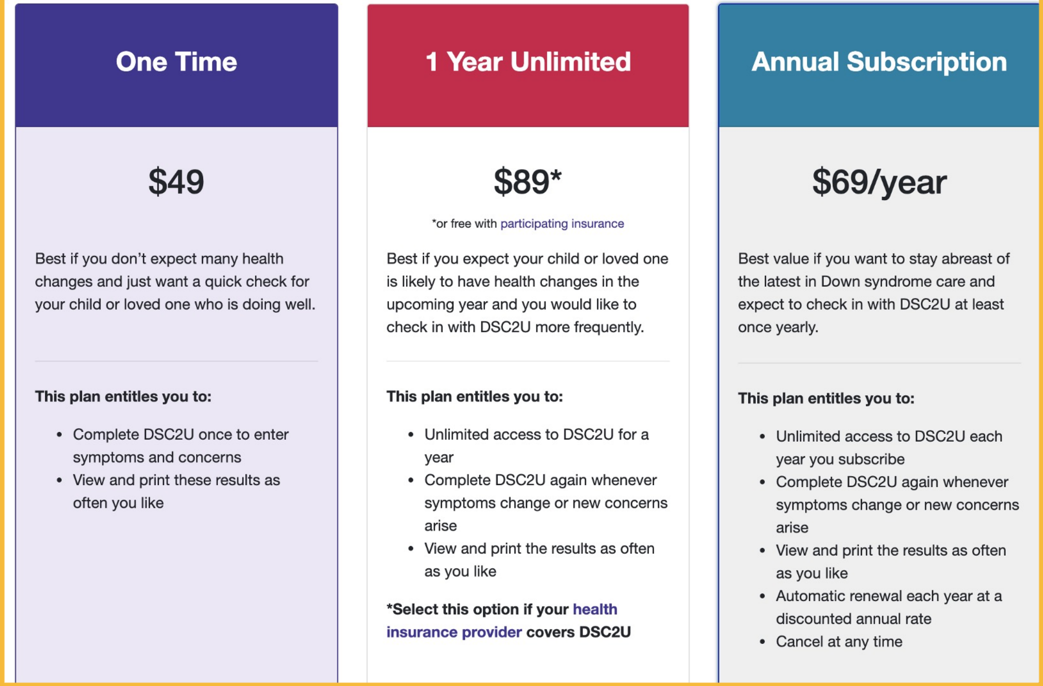


Potential New Conditions/Diagnoses to be Considered for Molly

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

- ☐ **Depression.** Molly's caregiver marked that within the past 6 months of completing our intake, Molly has experienced feeling down, depressed, or hopeless, little interest or pleasure in doing things, crying easily for no reason, moving slowly, distress about being alone. Generalized depression 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 can be eliminated.
- ☐ **Arthropathies.** Molly's caregiver indicated that within the past month of completing our intake, Molly has experienced joint stiffness, 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.
- ☐ **Chronic constipation.** Molly's caregiver indicated that within the past month of completing our intake, Molly experienced constipation that is hard to treat. Chronic constipation is a common feature in patients with Down syndrome and can lead to behavioral issues if left untreated. Consider obtaining a KUB and trying medication to alleviate the constipation if needed.

DSC2U has 3 low-cost options



One Time

$49

Best if you don't expect many health changes and just want a quick check for your child or loved one who is doing well.

This plan entitles you to:

- Complete DSC2U once to enter symptoms and concerns
- View and print these results as often you like

1 Year Unlimited

$89*

*or free with participating insurance

Best if you expect your child or loved one is likely to have health changes in the upcoming year and you would like to check in with DSC2U more frequently.

This plan entitles you to:

- Unlimited access to DSC2U for a year
- Complete DSC2U again whenever symptoms change or new concerns arise
- View and print the results as often as you like

***Select this option if your health insurance provider covers DSC2U**

Annual Subscription

$69/year

Best value if you want to stay abreast of the latest in Down syndrome care and expect to check in with DSC2U at least once yearly.

This plan entitles you to:

- Unlimited access to DSC2U each year you subscribe
- Complete DSC2U again whenever symptoms change or new concerns arise
- View and print the results as often as you like
- Automatic renewal each year at a discounted annual rate
- Cancel at any time

DSC2U is part of Mass General Brigham, a nonprofit healthcare system.

DSC2U is on a mission to make **high-quality healthcare guidance accessible to all**.

User fees support the operational costs that **keep this critical resource available** to families everywhere.

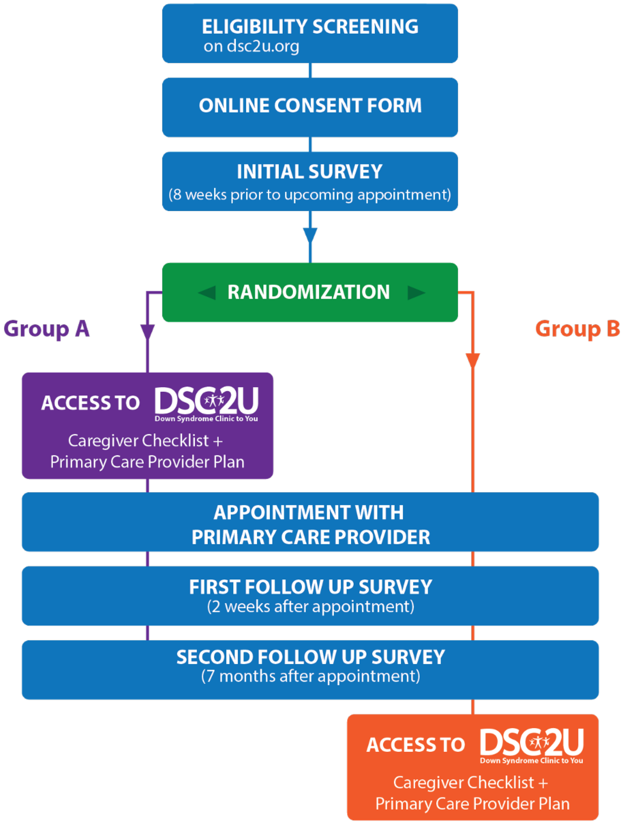
DSC2U
Down Syndrome Clinic to You

03

The impact

Families are catching missed issues and advocating with confidence.

We conducted a national randomized control trial to assess efficacy and satisfaction



ELIGIBILITY SCREENING
on dsc2u.org

ONLINE CONSENT FORM

INITIAL SURVEY
(8 weeks prior to upcoming appointment)

RANDOMIZATION

Group A

ACCESS TO DSC2U Down Syndrome Clinic to You
Caregiver Checklist +
Primary Care Provider Plan

Group B

APPOINTMENT WITH
PRIMARY CARE PROVIDER

FIRST FOLLOW UP SURVEY
(2 weeks after appointment)

SECOND FOLLOW UP SURVEY
(7 months after appointment)

ACCESS TO DSC2U Down Syndrome Clinic to You
Caregiver Checklist +
Primary Care Provider Plan

Specific Aim 1: To test whether a customizable Caregiver *Plan* and PCP *Letter* versus usual care will increase caregiver-reported, provider-driven health actions consistent with national guidelines.

Specific Aim 2: To determine whether a customizable *Plan* and *Letter* versus usual care is satisfactory to caregivers and providers and

Primary Outcomes

Thyroid: TSH should be checked annually beginning at age 1

Celiac disease: if symptoms present, obtain tTG-IgA and total IgA annually

Sleep study: performed by 4 years of age and, again, if symptomatic

Ophthalmology exam: annually, ages 1-5; every 2 years, ages 5-13; every 3 years, ages 13-21; every 2 years, ages 21 and older

Audiograms: annually up to age 21, every 2 years thereafter

Secondary Outcomes

Quality of life as measured by the nationally validated PedsQL survey instruments: PedsQL 2.0 Family Impact Module & PedsQL 4.0 parent-proxy, standard Short Form 15 Generic Core Scales.

Quality of Experience through caregiver and provider satisfaction surveys

DSC2U is effective

The group that received DSC2U **had a 1.6-fold increase** in the number of indicated evaluations that were recommended by the primary care provider or completed compared to controls.

No. of Assessments completed and/or recommended by PCP	Overall	Control	DSC2U	P-value
0	134 (62.0%)	77 (69.4%)	57 (54.3%)	0.004
1	67 (31.0%)	31 (27.9%)	36 (34.3%)	
2	13 (6.0%)	3 (2.7%)	10 (9.5%)	
3	2 (0.9%)	0 (0%)	2 (1.9%)	

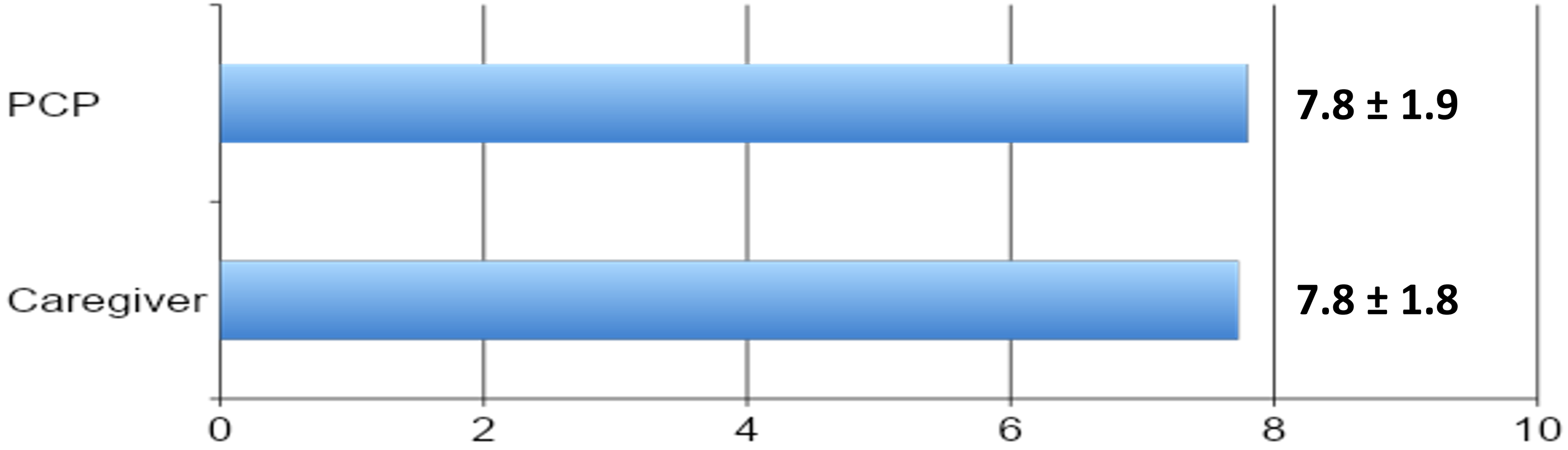
Caregivers are highly satisfied with DSC2U

Question	Yes, Definitely	Yes, Somewhat	No
Did Caregiver Checklist explain recommendations in a way that was **easy for you to understand**?	86%	11%	3%
Would you **recommend the DSC2U** to another caregiver of someone with Down syndrome?	83%	17%	0%
Did you **use the links** to information that were included in the Caregiver Checklist?	38%	39%	24%

Primary care physicians are too!

Question	Yes, Definitely	Yes, Somewhat	No
Did you **discuss this primary care plan** or any of its recommendations with the caregivers?	75%	25%	0%
Did you **agree with the recommendations** in this Plan?	61%	36%	3%
Were **you interested in any of the information** in this Plan?	71%	29%	0%

Overall, DSC2U had high rates of satisfaction from caregivers & PCPs



Using any number from 0 to 10, where 0 is the LEAST HELPFUL information possible and 10 is the MOST HELPFUL information possible, what number would you use to rate the CAREGIVER CHECKLIST or PRIMARY CARE PROVIDER PLAN?

Our results have now been published

ARTICLE | Genetics inMedicine

A randomized controlled trial of an online health tool about Down syndrome

Jeanhee Chung, MD[1,2], Karen Donelan, ScD, EdM[2,3], Eric A. Macklin, PhD[4], Alison Schwartz, MD[5,6], Ibrahim Elsharkawi, MD[5], Amy Torres, BS[5], Yichuan Grace Hsieh, PhD, RN[1,2], Holly Parker, BA[1], Stephen Lorenz, BA[1], Vasiliki Patsiogiannis, BA[5], Stephanie L. Santoro, MD[5,6], Mark Wylie, BA[1], Lloyd Clarke, BA[1], Greg Estey, BA[1], Sandra Baker[7], Patricia E. Bauer, BGS[8], Marilyn Bull, MD[9], Brian Chicoine, MD[10], Sarah Cullen, BA[11], Ariel Frey-Vogel, MD, MAT[6], Maureen Gallagher, MS[11], Reem Hasan, MD, PhD[12], Ashley Lamb, MD, MPH[13], Lisa Majewski, MSW, Jawanda Mast, MS, Travis Riddell, MD, MPH[14], Karen Sepucha, PhD[15], Melissa Skavlem, BA and Brian G. Skotko, MD, MPP[5,6]

https://rdcu.be/b6Hk4

Diversity, Equity, Inclusion in Healthcare

Our goal is to **better understand the barriers and facilitators** that face the Black/African American and primarily Spanish-speaking populations in accessing healthcare for their loved ones with Down syndrome.

We then hope to **create tangible solutions** to confront these barriers and better engage minority populations in their Down syndrome community and healthcare.

pcori® Patient-Centered Outcomes Research Institute

Our work was made possible by a 2-year Engagement Award from PCORI.

Black and Latino/s Caregivers often feel that quality of care is worse when compared to white patients with Down sy

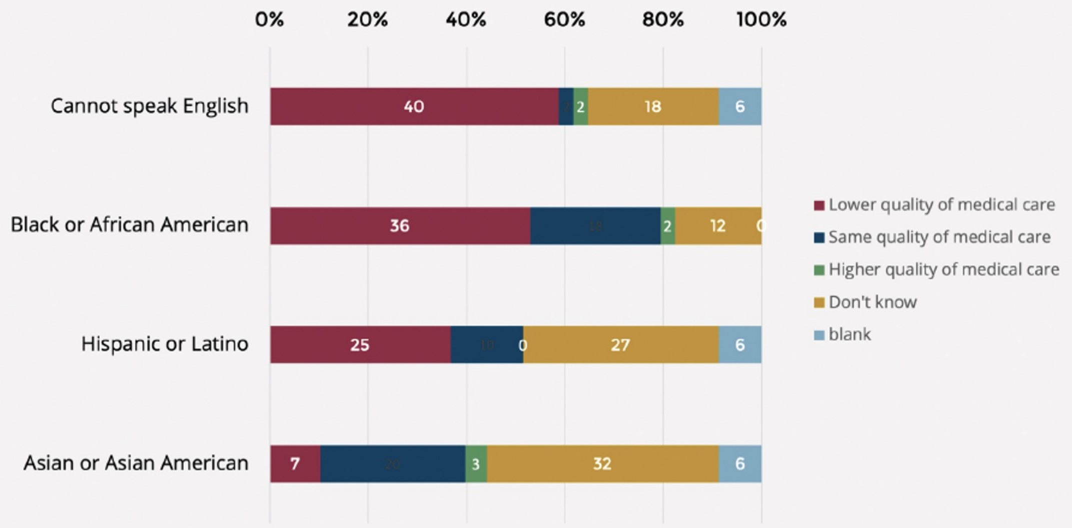


Figure 2. "For each of the following groups of patients with Down syndrome, do you think most receive a higher quality of medical care, same quality of medical care, or lower quality of medical care than most white patients with Down syndrome?" N = 68 people with Down syndrome who are Black, African American, of African descent, or of mixed race, as reported by their caregivers (counts per response choice listed in bars)

DSC2U can address many healthcare barriers mentioned by caregivers

Figure 5. "When your loved one with Down syndrome has been referred for a diagnostic test or appointment, have you worried about any of the following?" N = 68 people with Down syndrome who are Black, African American, of African descent, or of mixed race, as reported by their caregivers (counts per response choice listed in bars)

Doctors and hospitals can be trusted messengers

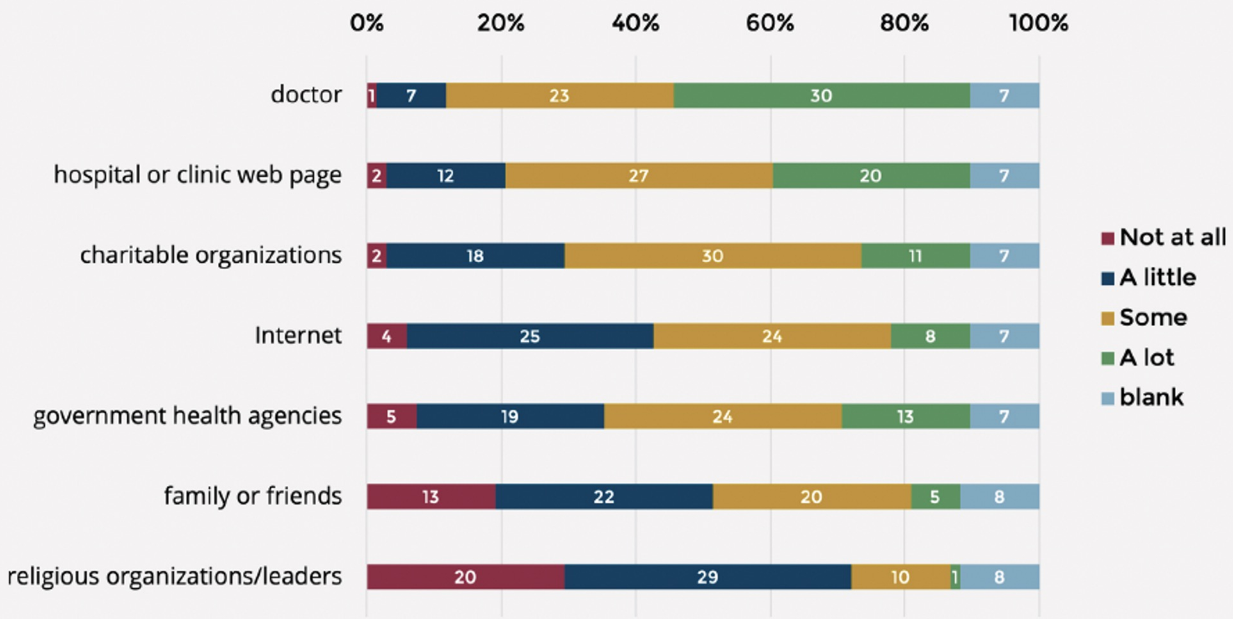


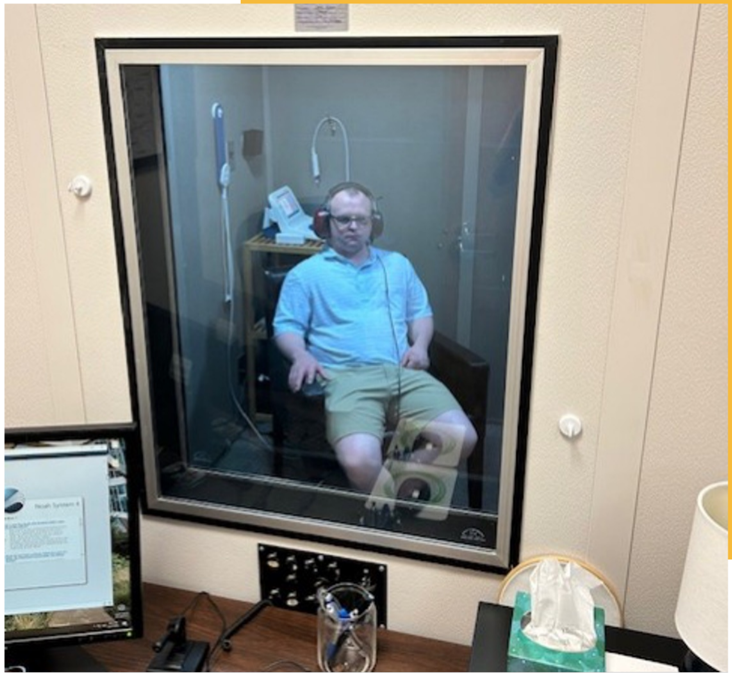
Figure 8. "In general, how much would you trust information about Down syndrome from each of the following?" N = 68 people with Down syndrome who are Black, African American, of African descent, or of mixed race, as reported by their caregivers (counts per response choice listed in bars).

Healthcare experiences of patients with Down syndrome who are Black, African American, of African descent, of mixed race, or come from primarily Spanish-speaking homes

This is what confidence looks like

BEFORE DSC2U

Ben hadn't seen an audiologist in years



AFTER DSC2U

He's now back on track with care

This is what peace of mind looks like

BEFORE DSC2U

Rob was having increased difficulty with walking

AFTER DSC2U

DSC2U flagged urgent need for a cervical x-ray. His caregiver scheduled one at his next appointment.

TESTIMONIALS

Don't just take our word for it! Caregivers have said:

"We were concerned because [my son's] new doctor ***had never seen an individual with Down syndrome before...***

Within 20 minutes we had a personalized checklist and plan—but most importantly, we had ***peace of mind*** *that [his] needs were going to be addressed."*

DSC2U

Down Syndrome Clinic to You

"35 year ago they told us 'Take her home and treat her like any other child.' Sounds lovely—but there are different things that need to be paid attention to...

DSC2U flagged concerns like sleep apnea and swallowing that had never come up before. ***This is how we keep moving forward.****"*

DSC2U

Down Syndrome Clinic to You

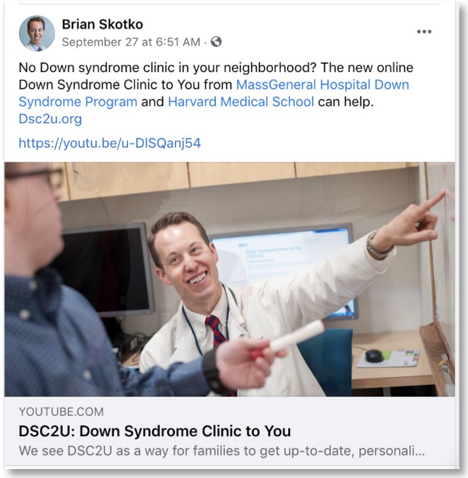
04

Call to Action

You can help others access this life-changing resource

How you can make a difference

- **Try DSC2U** for your loved one
- Spread the word about DSC2U on **social media.**
- Encourage your local DS organizations to:
    - Include information about DSC2U in their **next e-newsletter.**
    - Distribute our **DSC2U flyer** at in-person events.
    - **Offset the costs** for families in your area.



Brian Skotko
September 27 at 6:51 AM ·

No Down syndrome clinic in your neighborhood? The new online Down Syndrome Clinic to You from MassGeneral Hospital Down Syndrome Program and Harvard Medical School can help.
Dsc2u.org

https://youtu.be/u-DlSQanj54

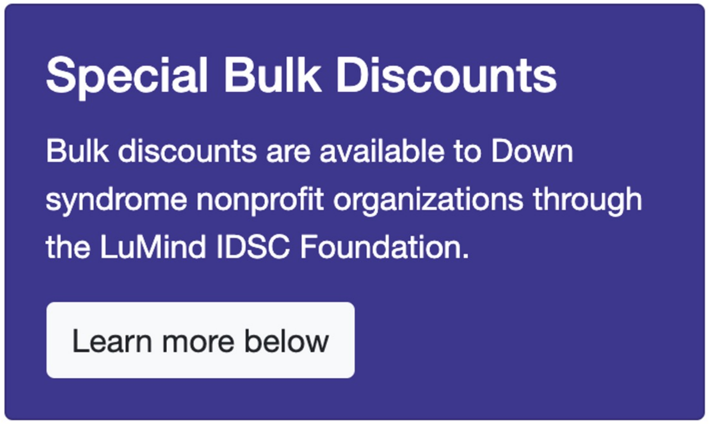
YOUTUBE.COM
DSC2U: Down Syndrome Clinic to You
We see DSC2U as a way for families to get up-to-date, personali...

MGH Down Syndrome @MGHDownSyndrome · Sep 23
Want the most up-to-date health and wellness information for your loved one with #Downsyndrome? Check out Down Syndrome Clinic to You (dsc2u.org), launched by Dr. @brianskotko and a team of experts @MGHDownSyndrome and @harvardmed.

DSC2U: A personalized care plan
Down Syndrome Clinic to You (DSC2U) brings the best of health and wellness information about Dow...
dsc2u.org

We have ready-to-go material for your social media pages and e-newsletters

Many Down syndrome organizations are purchasing discount codes to their members

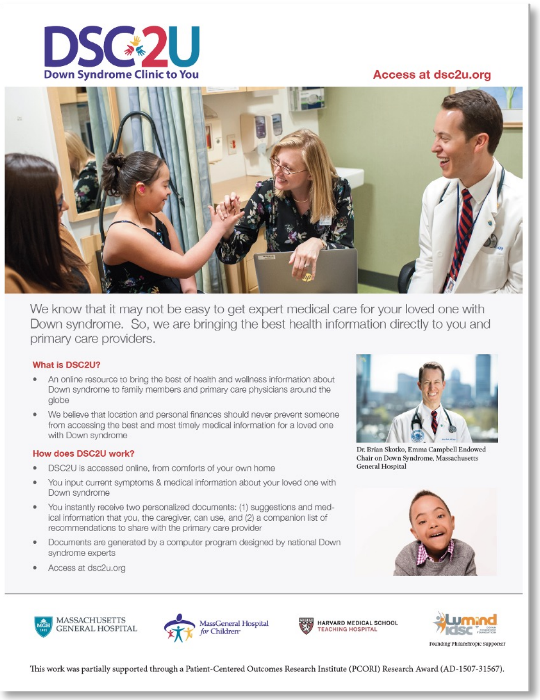


Special Bulk Discounts

Bulk discounts are available to Down syndrome nonprofit organizations through the LuMind IDSC Foundation.

dsc2u.org/organizations

Flyers available in English and Spanish



DSC2U
Down Syndrome Clinic to You

Access at dsc2u.org

We know that it may not be easy to get expert medical care for your loved one with Down syndrome. So, we are bringing the best health information directly to you and primary care providers.

What is DSC2U?

- An online resource to bring the best of health and wellness information about Down syndrome to family members and primary care physicians around the globe
- We believe that location and personal finances should never prevent someone from accessing the best and most timely medical information for a loved one with Down syndrome

How does DSC2U work?

- DSC2U is accessed online, from comforts of your own home
- You input current symptoms & medical information about your loved one with Down syndrome
- You instantly receive two personalized documents: (1) suggestions and medical information that you, the caregiver, can use, and (2) a companion list of recommendations to share with the primary care provider
- Documents are generated by a computer program designed by national Down syndrome experts
- Access at dsc2u.org

Dr. Brian Skotko, Emma Campbell Endowed Chair on Down Syndrome, Massachusetts General Hospital

MASSACHUSETTS GENERAL HOSPITAL
MassGeneral Hospital for Children
HARVARD MEDICAL SCHOOL TEACHING HOSPITAL
Lumind idsc
Founding Philanthropic Supporter

This work was partially supported through a Patient-Centered Outcomes Research Institute (PCORI) Research Award (AD-1507-31567).

DSC2U
Down Syndrome Clinic to You

Acceda en dsc2u.org

Sabemos que quizá no sea fácil obtener atención médica especializada para su ser querido con síndrome de Down. Por eso, le ofrecemos la mejor información de salud directamente a usted y a los proveedores de atención primaria.

¿Qué es DSC2U?

- Un recurso digital que le brinda la mejor información de salud y bienestar sobre el síndrome de Down a los miembros de la familia y a los médicos de atención primaria en todo el mundo.
- Creemos que la geografía y las finanzas personales nunca deben impedir que alguien acceda de forma oportuna a la mejor información médica para un ser querido con síndrome de Down.

¿Cómo funciona DSC2U?

- Se accede a DSC2U en línea, desde las comodidades de su propia casa.
- Usted completa un cuestionario con los síntomas actuales y la información médica sobre su ser querido con síndrome de Down.
- Usted recibe instantáneamente dos documentos personalizados: (1) sugerencias e información médica que usted, el cuidador, puede utilizar, y (2) una lista de recomendaciones para compartir con el proveedor de atención primaria.
- Los documentos son generados por un programa informático diseñado por expertos nacionales en síndrome de Down
- Acceda en dsc2u.org

Dr. Brian Skotko, Emma Campbell Presidente de la Cátedra de Síndrome de Down, Massachusetts General Hospital.

MASSACHUSETTS GENERAL HOSPITAL
MassGeneral Hospital for Children
HARVARD MEDICAL SCHOOL TEACHING HOSPITAL
Lumind idsc
Founding Philanthropic Supporter

Este trabajo fue parcialmente apoyado a través de un premio de investigación del Instituto de Investigación de Resultados Centrados en el Paciente (PCORI) (AD-1507-31567).

www.ndss.org/Resources/Health-Care

Together, we can democratize healthcare for people with Down syndrome - no matter where you live

We are stronger when we learn together. By using DSC2U, you're **sustaining this resource for other families** and helping doctors gain the knowledge they need to provide **better care**.

Our mission is to serve **100%** of people with Down syndrome.

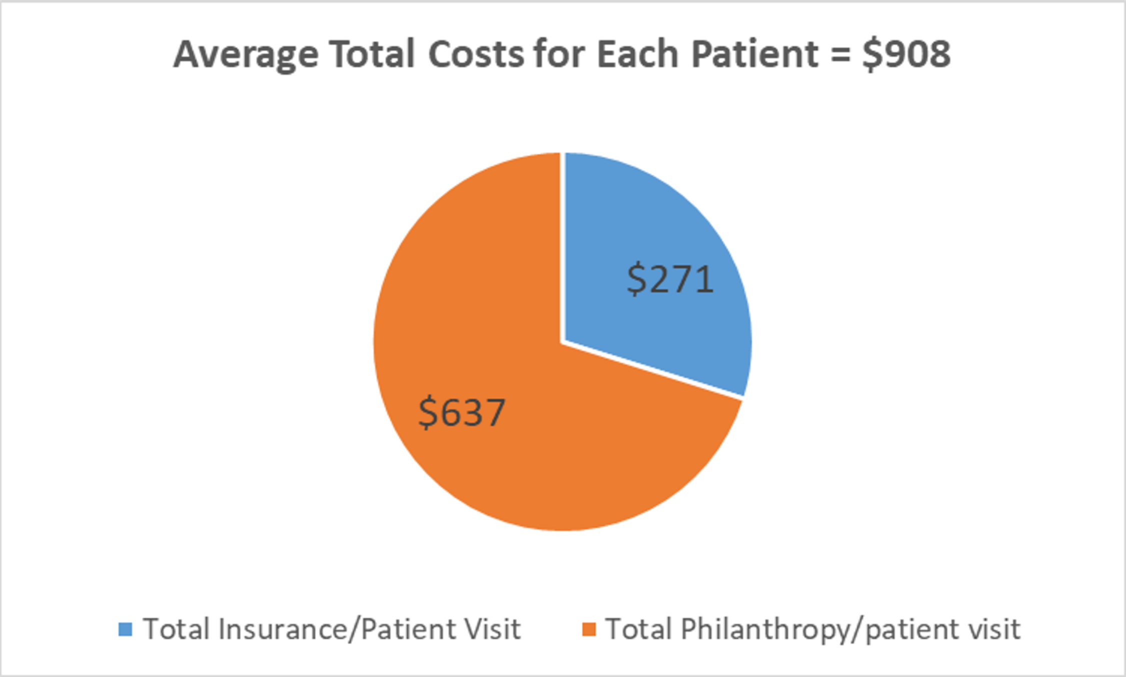
MassGeneral Hospital Down Syndrome Program

We also have an in-person clinic

Our goal is also to firmly endow our in-person clinic so that our team can continue to have the expertise to caretake DSC2U

Beyond insurance reimbursements, we need **$545,000** each year to sustain our in-person Program’s expenses.

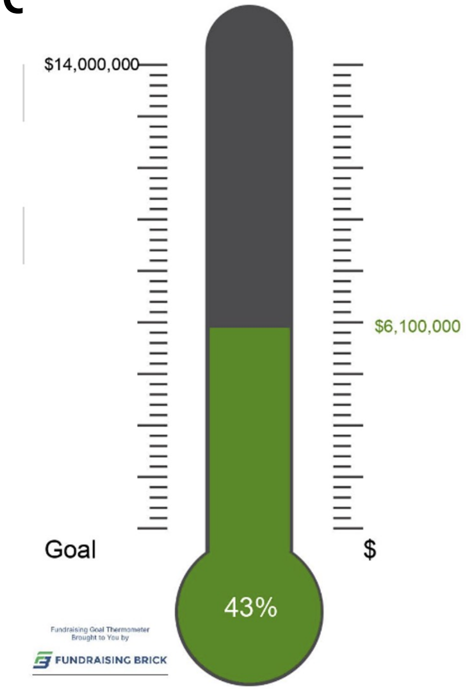
Costs to Run our In-person Clinics Exceed Insurance Revenue



Positions not fully supported by clinical revenue

- Nutritionists
- Program Manager
- Administrative Assistants
- Patient Service Coordinator
- Social Workers
- Resource Specialists (self-advocates)
- Educational advocate
- Psychiatrist

We need to secure about **$14 million** in our endowment to be able to permanently fund our current Program operations.



This current endowment yields about **$145,000** for us each year.

While waiting for our endowment to grow, we are grateful to our donors for "current use" funds

Overall, our Program needs to raise **~$400,000** annually (or about **$637 per visit**) to support our current clinical operations.

DSC2U can serve as a blueprint for many other diseases/conditions

We have already been contacted by physician experts in

- Marfan syndrome
- Adult Congenital Heart Disease
- Pediatric Allergies
- Neurofibromatosis

In short, any disease/condition with a medical playbook that needs management within primary care settings can benefit from our product.

Goal: DSC2U will be financially sustainable

We estimate that $2000K, per annum, is needed to sustain the operations of DSC2U at MGH.

3 Revenue Sources

- Direct user fees
- Insurance subsidization
- Full/partial discounts from Down syndrome organizations

THANK YOU!

DSC2U
Down Syndrome Clinic to You

Visit dsc2u.org for more

ALEXA SPOGNARDI, MS, MPH
E-mail: dsc2u@mgh.harvard.edu

BRIAN SKOTKO, M.D., M.P.P.
E-mail: bskotko@mgh.harvard.edu
Web page: www.brianskotko.com
Facebook: facebook.com/drbrianskotko
Twitter: twitter.com/brianskotko
YouTube: www.youtube.com/brianskotko
Clinic: www.massgeneral.org/downsyndrome
Research: www.massgeneral.org/downsyndromeresearch

Massachusetts General Hospital
Founding Member, Mass General Brigham

HARVARD
MEDICAL SCHOOL

DSC2U

Down Syndrome Clinic to You

Questions?