

An online personal care plan for caregivers and primary care physicians

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

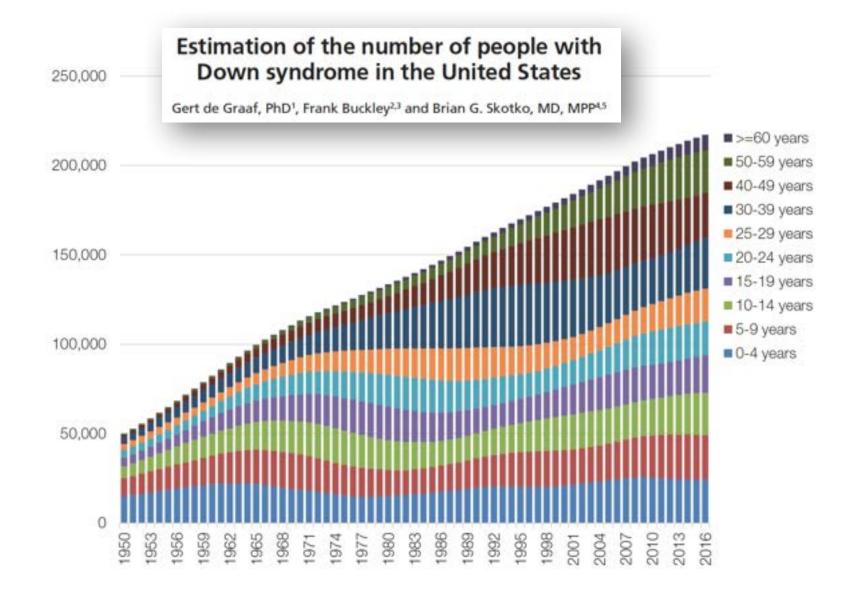


Patricia E. Bauer Mother

"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



There are 71 Down syndrome clinics in U.S.



www.ndss.org/Resources/Health-Care

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

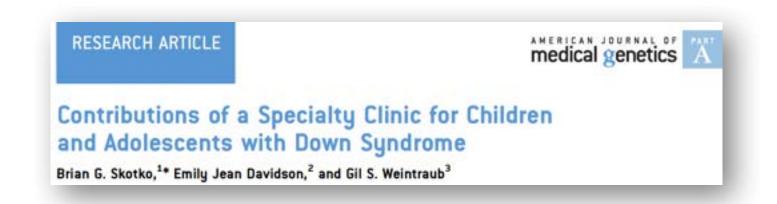
My sister is one of those patients who does not have access to a specialty clinic.

- I have a sister with Down syndrome.
- She is 41 years old.
- There are no adult Down syndrome clinics in Cleveland, where she lives with my parents.



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



We just completed a 3-year, \$2.1M project, funded by PCORI.



MassGeneral Hospital DSC2U Team



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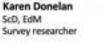
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National Advisory Groups Provided Critical Inputs

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Lisa Majewski, MSW Mother



Mother



Maureen Gallapher

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



dsc2u.org

1 General Information	
2 Current Medical Concerns	Virtual Clinic (October 5th version) General Information
3 Current Mental Health/Behavioral Concerns	Constantion data
4 immunizations	Information About the Patient
5 Nutrition	First name (inquired)
6 Past Medical History	Kristin
7 Blood work and Diagnostic Testing	Date of birth required
8 School and Therapies	08/20/1980
9 Life Skills Checklist	
10 Down Syndrome Community	Gender (required)
	C Female
	O 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

	a u 1	

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

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New limp

Increasing fatigue

Eyes

Concerns about vision

Involuntary eye movements

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 Gen	eral		CH11	100.01	

2 Current Medical Concerns

3 Current Mental Health/Behavioral Concerns

4 Bloodwork and Diagnostic Testing

5 Past Medical History

6 Immunizations

7 Nutrition and Swallowing

8 School, Therapies, and Resources

9 Life Skills Checklist

10 Down Syndrome Community

11 Feedback

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?

	4.1	_						
	Less	50	20	1	ner	175	AU.	
_		~	-		proc.	~	чx.	

- 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 det 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 calolum chew or multi-vitamin with calolum
- 3 or more per day
- Not sure

1 serving = 1 cup of milk, or fortified say 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: daily milk, fortified say 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

1 General Information Virtual Clinic (October 5th version) 2 Current Medical Concerns Sourcent Mental Health/Behavioral Concerns 3 Current Mental Health/Behavioral Concerns Has Kristin 4 Immunizations seen an audiologist for a formal hearing examination in the past 2 years? 5 Nutrition seen an audiologist for a formal hearing examination in the past 2 years? 6 Past Medical History Yes 7 Blood work and Diagnostic Testing No 8 School and Therapies seen an ophthalmologist for a formal eye examination in the past 2 years? 9 Life Skills Checklist Yes 10 Down Syndrome Community No Not sure ever had a sleep study performed for obstructive sleep apnea? Yes No Not sure ever had a sleep study performed for obstructive sleep apnea?		
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○ No		O Yes
		○ No
 Not sure 		O Not sure



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1. Caregiver Checklist for You

2. Primary Care Provider Plan to Share

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.





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NESS + RESOURCES + ENDOCRINE CONDITIONS & DOWN SYNDROME

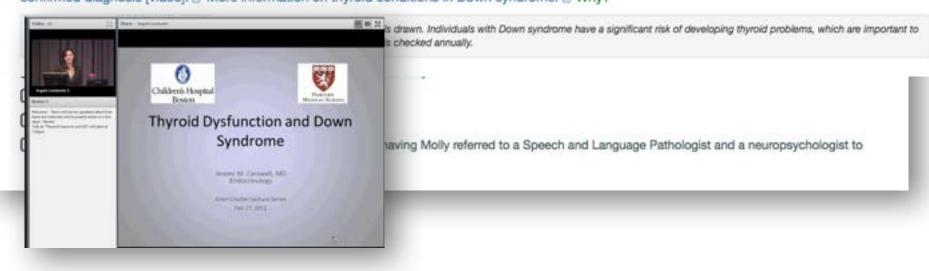
Endocrine Conditions & Down Syndrome

Labs, Tests, and Procedures for Molly

It is recommended that you ask Molly's doctor to consider ordering the following during the up

- Eye exam. Molly is due for a vision test by an eye doctor specialist. More info treatment options [video]. @ Why?
- Celiac screen (blood work). Molly has symptoms that might be consistent wi follow-up testing c. Treatment options are available for those with a confirme Why?
- 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

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?



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

What Is Hypothyroidism?

Hypothyroldism results from a maifunctioning 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?

Hypothyroldism is the most common endocrine problem in children with Down syndrome. It is estimated that approximately 10% of children with Down syndrome have compretation acquired thyrold disease. Hypothyroldism is also common in adults with Down syndrome and can lead to symptoms of fallpus, merral slugginhreas, weight fluctuations and intrability. Studies of adults with Down syndrome vary widely, but the invidence 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.

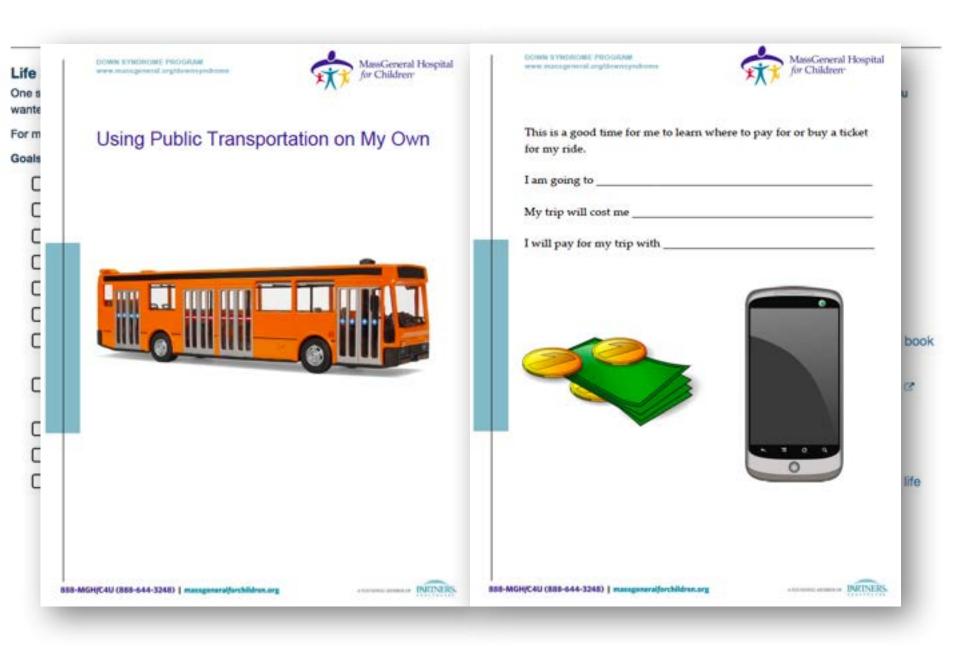


Nutrition Recommendations for Molly

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 r for a detailed overview on healthy nutrition for people with Down syndrome. Why?



Education/Therapy Resources for Molly

Recursos de educación/terapia para Molly

Cada año, los investigadores entienden mejor cómo aprenden las personas con síndrome de Down. Estos son algunos recursos específicos, basados en su solicitud, para Molly.

Habilidades del habla y la comunicación. Consulte el capítulo 6 de este libro c. Puede buscar fonoaudiólogos locales aquí c.

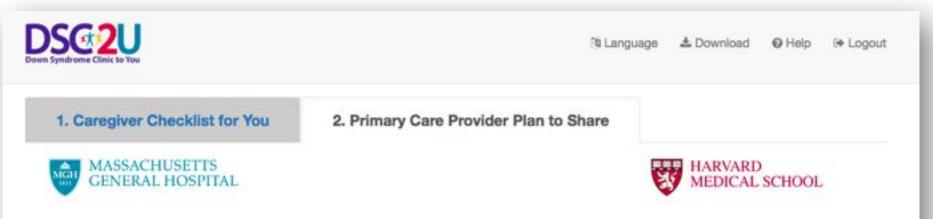
Habilidades de adaptación para la vida. Consulte el capítulo 9 de este libro c.

Habilidades vocacionales/oportunidades de empleo. Haga clic aquí para ver un resumen de las opciones de empleo @. Además, consulte los recursos de la campaña Your Next Star @, que incluyen recursos para los solicitantes @ y empleadores @. Estos son más recursos e historias de éxito de #DSWORKS® @. Para obtener más información sobre el empleo, consulte este sitio web @ y este manual @.

Información y recursos para el cuidador de Molly

Estos son algunos recursos específicos basados en su solicitud.

- DS-Connect®. Considere inscribir a Molly en DS-Connect @ para que esté en contacto con investigadores y proveedores de servicios de salud. ¿Por qué?
- 🔲 Global Down Syndrome Foundation. Encuentre más información en su sitio web. 🛛 Suscribase a su lista de correo. 🖉 ¿Por qué?
- LuMind Research Down Syndrome Foundation. Encuentre más información en su sitio web. @ Suscribase a su lista de correo. @ ¿Por qué?
- National Down Syndrome Congress (NDSC). Encuentre más información en su sitio web. 🖉 Suscribase a su lista de correo. 🕑 ¿Por qué?
- National Down Syndrome Society (NDSS). Encuentre más información en su sitio web. 2 ¿Por qué?
- Organización local de síndrome de Down. Puede acceder desde este enlace este enlace este encontrar una lista con todas las organizaciones de síndrome de Down en Estados Unidos. Podrá ver si hay una cerca de usted. ¿Por qué?
- Ingreso Suplementario de Seguridad Social (SSI). Consulte este kit para principiantes er para los adultos con discapacidades que solicitan beneficios a la seguridad social. Además, consulte este sitio web er para ver una guía paso a paso sobre cómo solicitar la SSI. ¿Por qué?



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.

OTHER INFORMATION, RESOURCES, and SUPPORTS for Molly

For your information, we provided Molly'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.

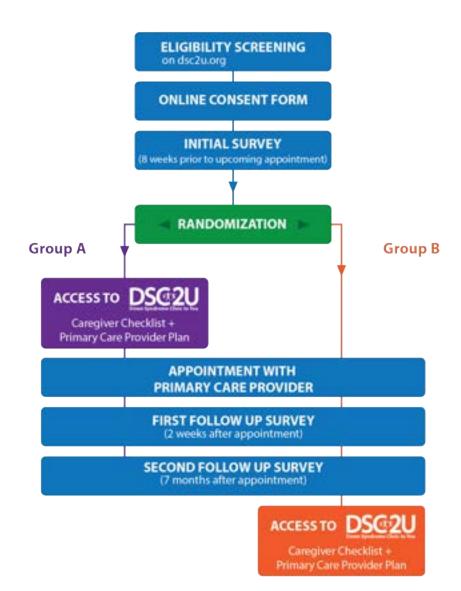
Health and Wellness Resources

- · Disruptive behaviors
- Oral-Contraceptive Pills (OCPs) for women with Down syndrome
- Dating and Social Boundaries
- Puberty and Sexual Development
- · Resources for weight gain in people with Down syndrome

Nutrition

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

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



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

Specific Aim 2: To determine whether a customizable *Plan* and *Letter* versus usual care is <u>satisfactory</u> to caregivers and providers and improves <u>quality of life</u> for caregivers/families.

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%)	

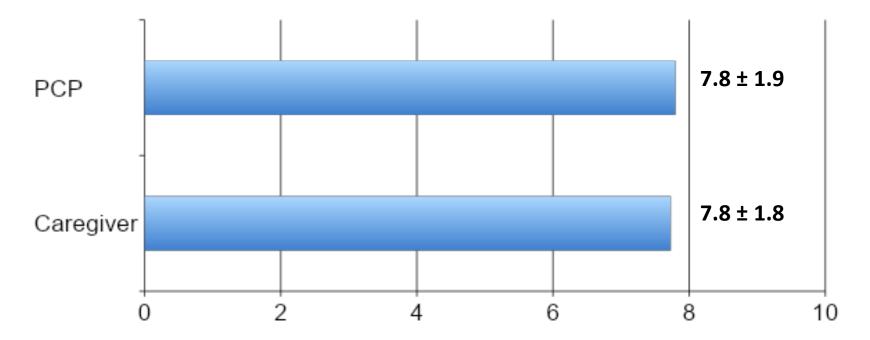
Caregivers are highly satisfied with DSC2U

Question	Yes, Definitely	Yes, Somewhat	Νο
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%

PCPs are satisfied with DSC2U

Question	Yes, Definitely	Yes, Somewhat	Νο
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

O American College of Medical Genetics and Genomics



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, PhD⁴, Alison Schwartz, MD^{5,6}, Ibrahim Elsharkawi, MD⁵, Amy Torres, BS⁵, Yichuan Grace Hsieh, PhD, RN^{1,2}, Holly Parker, BA¹, Stephen Lorenz, BA¹, Vasiliki Patsiogiannis, BA⁵, Stephanie L. Santoro, MD^{5,6}, Mark Wylie, BA¹, Lloyd Clarke, BA¹, Greg Estey, BA¹, Sandra Baker⁷, Patricia E. Bauer, BGS⁸, Marilyn Bull, MD⁹, Brian Chicoine, MD¹⁰, Sarah Cullen, BA¹¹, Ariel Frey-Vogel, MD, MAT⁶, Maureen Gallagher, MS¹¹, Reem Hasan, MD, PhD¹², Ashley Lamb, MD, MPH¹³, Lisa Majewski, MSW, Jawanda Mast, MS, Travis Riddell, MD, MPH¹⁴, Karen Sepucha, PhD¹⁵, Melissa Skavlem, BA and Brian G. Skotko, MD, MPP⁵

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.



Patient-Centered Outcomes Research Institute

Our work is 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 syndrome.

- 59% of caregivers feels that patients with Down syndrome who do not speak English receive lower quality of medical care than most white patients with Down syndrome.
- **53%** of caregivers feels that patients with Down syndrome **who are black** receive lower quality of medical care than most white patients with Down syndrome.
- 37% of caregivers feels that patients with Down syndrome who are are Latino/a receive lower quality of medical care than most white patients with Down syndrome

DSC2U has been launched!



Founding Philanthropic Supporter

dsc2u.org

All families across the globe can access DSC2U right now in English and Spanish



dsc2u.org

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*

for 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



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.

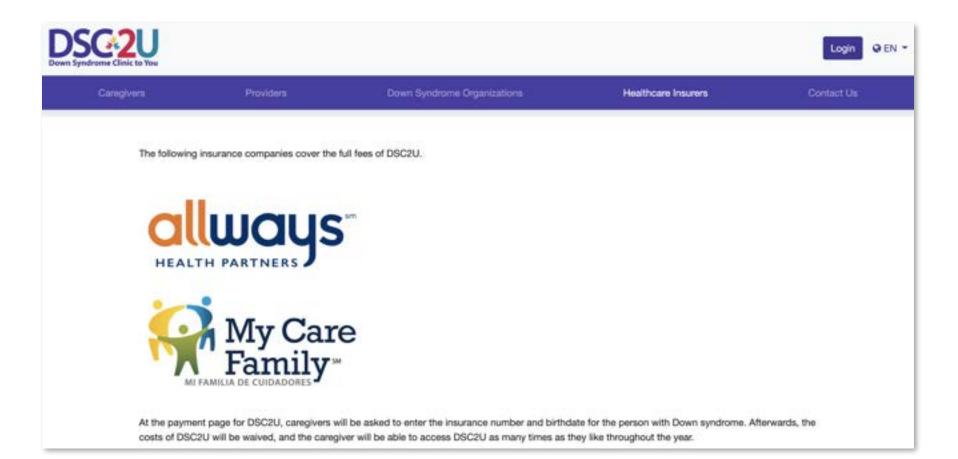
Learn more below

dsc2u.org/organizations

DSC2U is now covered by some insurers

- AllWays Healthcare has committed to having DSC2U fully covered for its families
- We have the capability of doing real-time insurance eligibility check on DSC2U prior to payment
- Our team has started conversations with United Healthcare/Optum and National Health Services (UK)

dsc2u.org/insurers



www.dsc2u.org/insurers

How you can make a difference

- 1. Spread the word about DSC2U on social media.
- **1.** Include information about DSC2U in your **next e-newsletter.**
- **1.** Distribute our **DSC2U flyer** at your in-person membership events.
- 1. Offset the costs for families in your area.

dsc2u.org/organizations

Please help us spread the word about DSC2U dsc2u.org/socialmedia



Down Syndrome Clinic to You from MissoGeneral Haspital Down Syndrome Program and Harverd Medical School can help. Declauorg

https://youtu.be/u-DISGan/54



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

facebook.com/drbrianskotko

MassGeneral Hospital Down Syndrome Program

Don't have a Down syndhome specialty clinic rearrhy? hou can now get the storet health and wellness information million from Down Syndhome Clinic to the Use (StaDurny), created by Dr. than Stores and a team of experts here and at stores the doct of broad.

"No tiene una clinica carcana especializada en sindrone de Doen? Ahora puede obtener la información máx reciente aubre salud y bienestrar en lisea por media de la Cinicia virtual de Sindrome de Doen para Usted<u>SinC20.org1</u>, oreada p... **See More**

See Translations



www.facebook.com/MGHDownSyndrome/



twitter.com/MGHDownSyndrome



twitter.com/brianskotko

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

Social Media Blurbs https://dsc2u.org/socialmedia

Newsletter Material https://dsc2u.org/newsletter

YouTube Videos English: <u>https://youtu.be/u-DISQanj54</u> Spanish: <u>https://youtu.be/nYp0oI2VGCo</u>

Overall Toolkit <u>https://docs.google.com/document/d/</u> <u>lgngeF8921woW19FcdspFR3PEU9d86GpoYMRYLZ-pD98/edit?</u> <u>usp=sharing</u>

Flyers available in English and Spanish





https://dsc2u.org/assets/documents/en/MGHfC-DSC2U-Provider-Handout-English.pdf https://dsc2u.org/assets/documents/es/MGHfC-DSC2U-Provider-Handout-Spanish.pdf

Thank you

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