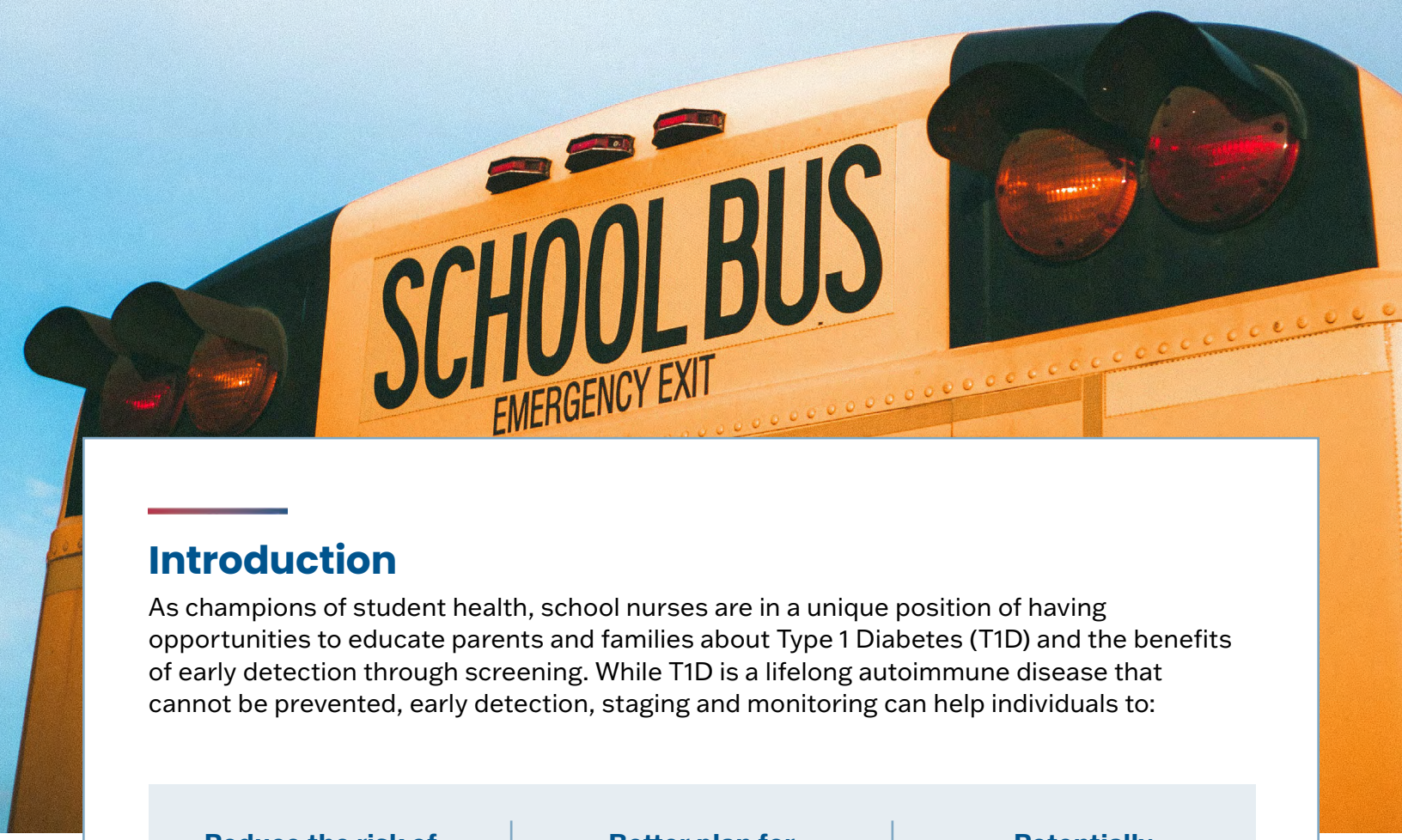
Type 1 Diabetes Awareness Toolkit:

EDUCATING FAMILIES ABOUT EARLY DETECTION SCREENING FOR TYPE 1 DIABETES

NASN
National Association of School Nurses

nasn.org



Introduction

As champions of student health, school nurses are in a unique position of having opportunities to educate parents and families about Type 1 Diabetes (T1D) and the benefits of early detection through screening. While T1D is a lifelong autoimmune disease that cannot be prevented, early detection, staging and monitoring can help individuals to:

Reduce the risk of life-threatening complications and hospitalization

Better plan for and manage a potential diagnosis

Potentially participate in research trials to advance management of the disease

Family history is the highest risk factor – having a parent, sibling, or child with T1D increases your risk of developing T1D by up to 15 times.

While those with a family history of T1D present a greater risk for developing the disease, approximately 90% of people diagnosed with T1D have no family history at all.

A T1D diagnosis can happen suddenly and unexpectedly. Through screening, the risk for T1D can be detected early – potentially years before a child begins experiencing symptoms. Screening and monitoring can also significantly reduce the incidence of diabetic ketoacidosis (DKA), a serious complication of T1D, among those newly diagnosed.[1,2]

The following resources are available to assist school nurses and other school leaders in educating parents about T1D and T1D screening options to facilitate conversations with their family's healthcare provider.

1. Sims, E.K., Besser, R.E.J., Dayan, C., Rasmussen, C.G., Greenbaum, C., Griffin, K.J., Hagopian, W., Knip, M., Long, A.E., Martin, F., Mathieu, C., Rewers, M., Steck, A.K., Wentworth, J.M., Rich, S.S., Kordonouri, O., Ziegler, A.-G., Herold, K.C., (2022). Screening for Type 1 Diabetes in the General Population: A Status Report and Perspective. Diabetes 71 (4): pp.610–623. https://doi.org/10.2337/dbi20-0054
2. Cherubini V, Scaramuzza AE, Agrimi U, et al. Initial observations on the frequency of diabetic ketoacidosis following pilot screening for type 1 diabetes in the general Italian population. Diabetes, obesity & metabolism. 2025;27(10):6039-6043. doi:10.1111/dom.16611

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Acknowledgements

This activity is supported by a contribution from Sanofi.

PART 1: INTRODUCTION TO TYPE 1 DIABETES (T1D) FOR SCHOOL NURSES

Evidence-based information about T1D and T1D screening

Type 1 Diabetes (T1D) is a lifelong autoimmune disease that attacks healthy insulin-producing beta cells in the pancreas needed to regulate blood sugar.[1] Without insulin, blood sugar can't get into cells and builds up in the bloodstream, which is damaging to the body.[2]

TID is a significant chronic condition, with an estimated 2.1 million Americans living with diagnosed T1D. This includes some 1.8 million adults and 314,000 children and youth younger than age 20 (Centers for Disease Prevention and Control, 2026). T1D continues to demonstrate growth across age groups, with incidence increasing worldwide by 2.4% in 2025 (Ogle et al, 2025).[3]

How is T1D screening conducted?

Studies indicate that measuring pancreatic islet autoantibodies (AAbs), indicators of beta cell autoimmunity, through a blood test can effectively identify those who will develop T1D. This is different than measuring blood sugar levels, which are only elevated in later stages of the disease. With the presence or history of two or more autoantibodies, measurement of glucose levels can be used to identify the individual's T1D stage.[4]

Why get screened?

A T1D diagnosis can happen suddenly and unexpectedly. Today, most people are not diagnosed until Stage 3, when symptoms of high blood sugar appear and insulin dependence begins.[3] Although rare, undiagnosed T1D can lead to diabetic ketoacidosis (DKA), a serious complication of T1D, and can potentially be fatal.[6]

While T1D is not preventable, the risk for T1D is detectable in Stages 1 and 2. The autoimmune-mediated attack on insulin-producing cells is represented by pancreatic-islet autoantibodies, which can be detectable months to years before a person begins experiencing symptoms.

Common Symptoms of T1D:

1. Excessive thirst
2. Frequent urination
3. Unexplained weight loss
4. Exhaustion
5. Blurred vision
6. Feeling very hungry
7. Mood changes

Stage 1:[5]

1. ≥2 AAbs
2. No symptoms present
3. Regulating blood glucose levels without difficulty (Normoglycemia)

Stage 2:[5]

1. ≥2 AAbs
2. No symptoms present
3. Experiencing difficulty regulating blood glucose normally (Dysglycemia)

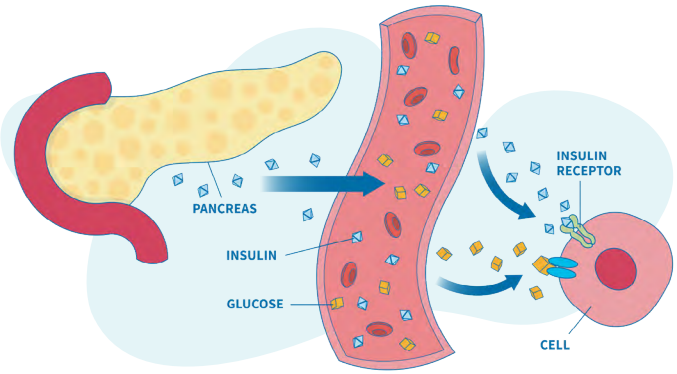
Stage 3:[5]

1. Autoimmunity and positive AAbs in most
2. Symptoms present
3. Elevated blood glucose levels (Hyperglycemia); diabetes by standard criteria

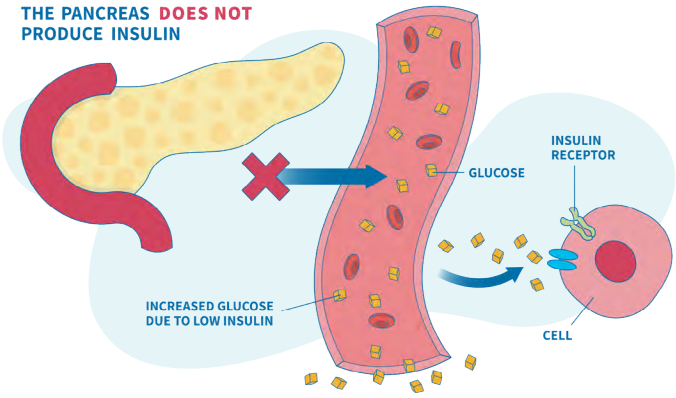
1. Breakthrough T1D: Type 1 diabetes basics. https://www.breakthrought1d.org/t1d-basics/
2. Centers for Disease Control and Prevention. (2026, January 21). National diabetes statistics report. U.S. Department of Health and Human Services. Retrieved February 21, 2026, from https://www.cdc.gov/diabetes/php/data-research/index.html
3. Ogle, G. D., et a. (2025). Global type 1 diabetes prevalence, incidence, and mortality estimates 2025: Results from the International diabetes Federation Atlas, 11th Edition, and the T1D Index Version 3.0. Diabetes Research and Clinical Practice, 225, 112277. https://doi.org/10.1016/j.diabres.2025.112277
4. Beyond Type 1. (2023). Different States Type 1 Diabetes. https://beyondtype1.org/different-stages-type-1-diabetes/
5. American Diabetes Association Professional Practice Committee. (2026). Diagnosis and Classification of Diabetes: Standards of care in diabetes—2026. Diabetes Care, 49(Suppl. 1), S27-S49.
6. Sims, E. K., et al. (2022). Screening for type 1 diabetes in the general population: A status report and perspective. Diabetes, 71(4), 610–623.

What is Type 1 Diabetes?

TYPICAL



TYPE 1



Who is at risk for T1D?

Family history is the highest risk factor – having a parent, sibling, or child with T1D increases your risk of developing T1D by up to 15 times.

While those with a family history of T1D present a greater risk for developing the disease, approximately 90% of people diagnosed with T1D have no family history at all.[1,2]

Where can families access screening?

Several screening options are available in the U.S.

- **Commercial Labs:**[2] Local commercial lab, such as LabCorp or Quest Diagnostics
- **TrialNet:**[2] TrialNet location, event or health fair – or test kit to use at home and bring to commercial labs (at no cost to relatives of people with T1D)
- **Autoimmunity Screening for Kids:**[4,5] Free screening available to U.S. residents aged 1+ with or without a family history of T1D – through Barbara Davis Center for Diabetes and at-home screening kits
- **General Screening Programs, Table 1**[1]

**This is not an exhaustive list of screening options. Inclusion on this list does not imply an endorsement of a particular laboratory or screening method.*

What tests should families request?

If the family chooses to conduct autoantibody screening at their healthcare provider's office or a local lab, Breakthrough T1D suggests providing the healthcare provider with the following lab test information:[6]

Labs to Order (4)

Insulin Autoantibody (IAA)-CPT 86337
Glutamic Acid Decarboxylase (GAD) Autoantibody-CPT 86341
Islet Antigen 2 (IA-2) Autoantibody-CPT 86341
Zinc Transporter 8 (ZnT8) Autoantibody-CPT 86341

Related Diagnosis Codes

Z83.3 - Family history of diabetes
R73.9 - Hyperglycemia, unspecified
Z13.1 - Screening for diabetes mellitus

What do the results suggest?

If ≤1 autoantibody (AAb) detected:[6]
Families may consider having their child who is under 15 re-screened every 6 months to year. Positive Islet Antigen 2 (IA-2) requires close monitoring.

If ≥2 autoantibodies (AAb) detected:[6]
A high risk of progression to Stage 3 TID. Therefore, families should talk to their child's healthcare provider about confirmatory testing, establishing a monitoring plan, and options for management.

1. Sims, E.K., Besser, R.E.J., Dayan, C., Rasmussen, C.G., Greenbaum, C., Griffin, K.J., Hagopian, W., Knip, M., Long, A.E., Martin, F., Mathieu, C., Rewers, M., Steck, A.K., Wentworth, J.M., Rich, S.S., Kordonouri, O., Ziegler, A.-G., Herold,K.C. (2022). Screening for Type 1 Diabetes in the General Population: A Status Report and Perspective. Diabetes 71 (4): pp. 610–623. https://doi.org/10.2337/dbi20-0054
2. Ogle, G. D., et a. (2025). Global type 1 diabetes prevalence, incidence, and mortality estimates 2025: Results from the International diabetes Federation Atlas, 11th Edition, and the T1D Index Version 3.0. Diabetes Research and Clinical Practice, 225, 112277. https://doi.org/10.1016/j.diabres.2025.112277
3. The Association of Diabetes Care & Education Specialists. (2025). The Role of the Diabetes Care and Education Specialist in Screening and Monitoring for Type 1 Diabetes. The Science of Diabetes Self-Management and Care, 51(3), 345–351. https://doi.org/10.1177/26350106251337489
4. Barbara Davis Center for Diabetes (n.d.). Autoimmunity Screening for Kids: Screening Locations. https://www.askhealth.org/locations
5. McQueen, R.B., Rasmussen, C.G., Waugh, K., Frohnert, B.I., Steck, A.K., Yu, L., Baxter, J., Rewers; M. (2020). Cost and Cost-effectiveness of Large-scale Screening for Type 1 Diabetes in Colorado. Diabetes Care 43 (7): pp. 1496–1503. https://doi.org/10.2337/dc19-2003
6. American Diabetes Association Professional Practice Committee (2024). Diagnosis and Classification of Diabetes: Standards of Care in Diabetes—2024. Diabetes Care 47 (Supplement_1). S20–S42. https://doi.org/10.2337/dc24-S002

T1D Decision Tree for School Nurses

Type 1 Diabetes (T1D) is a lifelong autoimmune disease that attacks healthy insulin-producing cells in the pancreas needed to regulate blood sugar.[1] Without insulin, blood sugar can't get into cells and builds up in the bloodstream, which is damaging to the body.[2]

Common Symptoms of T1D:

1. Excessive thirst
2. Frequent urination
3. Unexplained weight loss
4. Exhaustion
5. Blurred vision
6. Feeling very hungry
7. Mood changes

When the school nurse is having a conversation with a parent/caregiver regarding T1D concerns

Does the individual have symptoms?

Yes

Recommend parents/caregivers see their child's healthcare provider **immediately** to talk about symptoms and getting screened for T1D

No

Recommend parents/caregivers talk to their child's healthcare provider about T1D screening options

Does the individual have a family history of T1D?

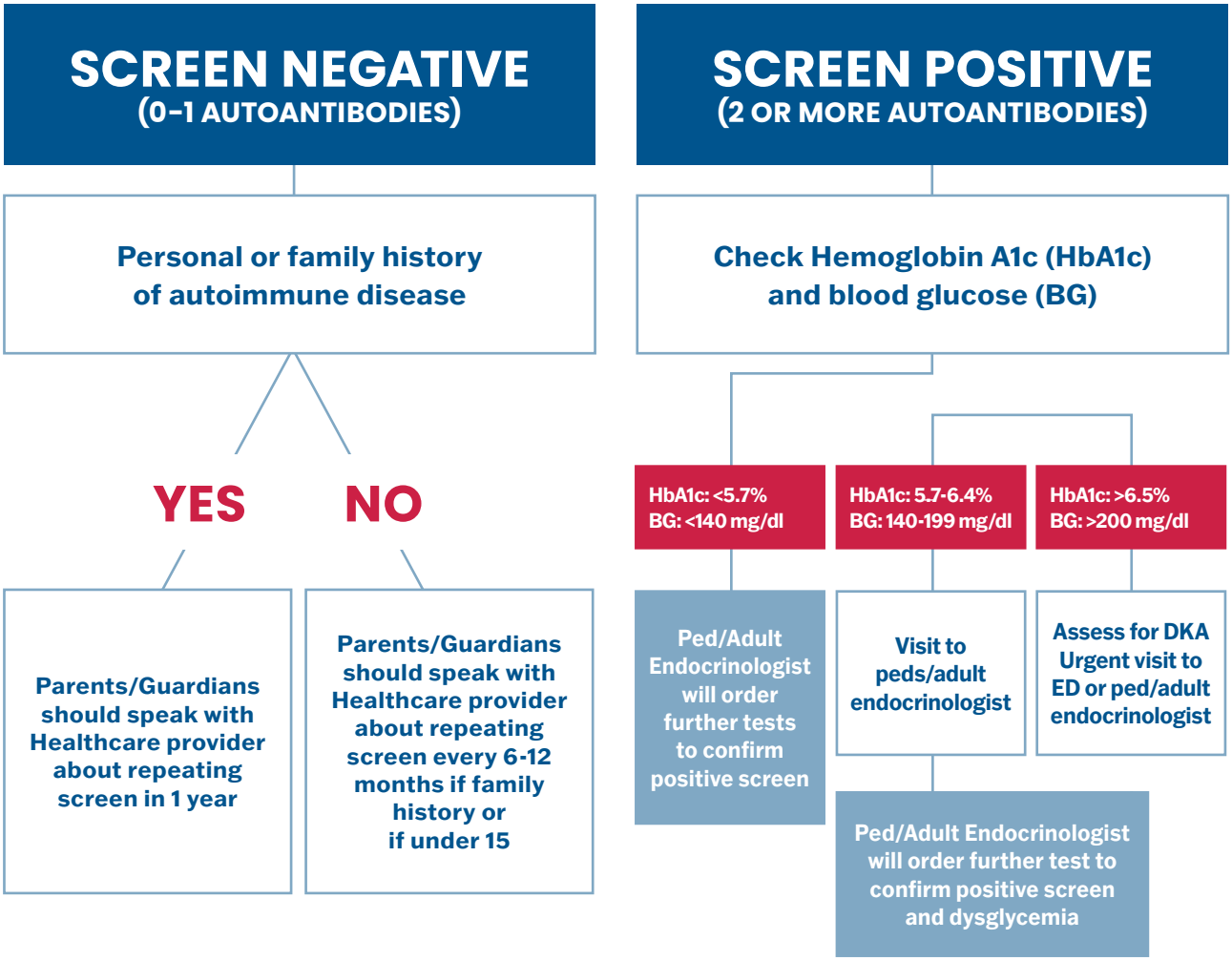
Recommend parents/caregivers talk to their healthcare provider about getting screened for T1D.

- Family history is the highest risk factor – having a parent, sibling, or child with T1D increases your risk of developing T1D by up to 15 times.
- However, approximately 90% of people diagnosed with T1D have no family history at all.

1. Breakthrough T1D: Type 1 diabetes basics. https://www.breakthrought1d.org/t1d-basics/
2. Centers for Disease Control and Prevention. (2024, May 15). About Type 1 Diabetes. https://www.cdc.gov/diabetes/about/about-type-1-diabetes.html

Screening Algorithm[1]

The algorithm shown here is intended for the management of a person screened for T1D. **It is not intended for use by the school nurse, but serves as an example of the healthcare provider's protocol in determining next steps upon return of patient's screening results.**



1. Simmons, K. M. W., Frohnert, B. I., O'Donnell, H. K., Bautista, K., Geno Rasmussen, C., Gerard Gonzalez, A., Steck, A. K., & Rewers, M. J. (2023). Historical Insights and Current Perspectives on the Diagnosis and Management of Presymptomatic Type 1 Diabetes. Diabetes technology & therapeutics, 25(11), 790–799. https://doi.org/10.1089/dia.2023.0276

Referral Information for School Nurses

When to refer a student for T1D screening

If you have a student that has familial risk for T1D and/or is experiencing T1D symptoms:

1. **Contact** parent/caregiver about your health concerns
2. **Refer** to healthcare provider for testing and treatment of symptoms
3. **Offer resources,** such as online T1D resources for caregivers, caregiver Q&A and T1D one pagers, as available in this toolkit
4. **Follow up with families** to identify local testing locations and review screening options

Information on screening options/locations

1. **Commercial Labs:**[1] Local commercial lab, such as LabCorp or Quest Diagnostics
2. **TrialNet:**[1] TrialNet location, event or health fair – or test kit to use at home and bring to commercial labs (at no cost to relatives of people with T1D)
3. **Autoimmunity Screening for Kids:**[2,3] Free screening available to U.S. residents aged 1+ with or without a family history of T1D – through Barbara Davis Center for Diabetes and at-home screening kits
4. **General Screening Programs, Table 1**[4]

**This is not an exhaustive list of screening options. Inclusion on this list does not imply an endorsement of a particular laboratory or screening method.*

1. Scheiner, G., Weiner, S.M., Kruger, D.F., & Pettus, J.H. (2022). Screening for Type 1 Diabetes: Role of the Diabetes Care and Education Specialist. ADCES in Practice, 10, 20 - 25.
2. Barbara Davis Center for Diabetes (n.d.). Autoimmunity Screening for Kids: Screening Locations. https://www.askhealth.org/locations
3. McQueen, R.B., Rasmussen, C.G., Waugh, K., Frohnert, B.I., Steck, A.K., Yu, L., Baxter, J., Rewers; M. (2020). Cost and Cost-effectiveness of Large-scale Screening for Type 1 Diabetes in Colorado. Diabetes Care 43 (7): pp. 1496–1503. https://doi.org/10.2337/dc19-2003
4. Sims, E.K., Besser, R.E.J., Dayan, C., Rasmussen, C.G., Greenbaum, C., Griffin, K.J., Hagopian, W., Knip, M., Long, A.E., Martin, F., Mathieu, C., Rewers, M., Steck, A.K., Wentworth, J.M., Rich, S.S., Kordonouri, O., Ziegler, A.-G., Herold,K.C. (2022). Screening for Type 1 Diabetes in the General Population: A Status Report and Perspective. Diabetes 71 (4): pp. 610–623. https://doi.org/10.2337/dbi20-0054

Online T1D Resources for School Nurses

The following are online resources about T1D and T1D screening intended to help support school nurses when talking to parents about T1D and screening benefits/options:

T1D Info and Standards of Care

- Type 1 Diabetes (ADA)
- Classification and Diagnosis of Diabetes: Standards of Care in Diabetes (ADA)
- School Nursing Evidence-Based Clinical Practice Guideline: Students with T1D
- The Role of the Diabetes Care and Education Specialist in Screening and Monitoring for Type 1 Diabetes

School Personnel Guidance

- Type 1 Diabetes Help for Teacher & Educators (Breakthrough T1D)
- Training Resources for Schools (ADA)
- School Nursing Evidence-Based Clinical Practice Guideline: Students with Type 1 Diabetes Toolkit (NASN)

T1D Screening

- Screening for T1D (Beyond Type 1)
- Screen for Type 1: What to Know About Type 1 Diabetes screening
- Trialnet.org
- Screening Follow-Up Flow Chart, Figure 1 (Diabetes Technology & Therapeutics)

PART 2:
HELPFUL HANDOUTS FOR PARENTS/CAREGIVERS

T1D Parent/Caregiver Q&A

What is Type 1 Diabetes?

TYPICAL

- In the human body, there is an organ called the pancreas.
- The pancreas makes insulin.
- When you eat, your body digests some foods to make glucose (sugar) that is carried in your blood.
- Blood glucose is used by your body's cells as energy.
- Insulin moves the glucose from your blood into the cells.

TYPE 1

In type 1 diabetes, the pancreas does not make enough insulin. This can cause high levels of glucose in the blood.

- High levels of glucose in the blood is called "hyperglycemia."
- Hyperglycemia over long periods of time can damage the body. This can cause symptoms and complications.

What is the difference between Type 1 and Type 2 Diabetes?

There are different types of diabetes and the most commonly known are Type 1 and Type 2. Both affect how the body controls blood sugar, but they are not the same condition. Type 1 the body stops making insulin and to treat the individuals have to take insulin everyday. Type 2 the body still makes insulin but it doesn't use it well. They have different causes and treatments.

What causes T1D?

Type 1 diabetes is caused by the immune system attacking insulin-making cells. It is not preventable and not caused by lifestyle choices. Family history and other factors may play a role, but the exact cause of the body attacking these cells is not fully known.

What are the warning signs and symptoms of Type 1 diabetes?

- Increase in thirst.
- Increase in urination.
- Bed wetting in children who did not do that before.
- Increase in hunger, even after eating.
- Unexplained weight loss.
- Feeling very tired.
- Blurry vision.
- Dry Mouth.
- Itchy or Dry Skin.
- Fruity breath.
- Dry or flushed skin.
- Feeling sick to stomach.
- Vomiting.
- Stomach pain.
- Trouble breathing.
- Confusion.

When are most people diagnosed with Type 1 Diabetes?

A T1D diagnosis can happen suddenly and unexpectedly. T1D develops in three stages. Talk to your healthcare provider if you think your child may have symptoms of T1D. A variety of tests may be performed to confirm the diagnosis. Blood sugar levels are measured and, if elevated, may require insulin injections.

T1D Screening Parent/Caregiver Q&A

Who is at risk for T1D?

T1D can affect people of all ages. The biggest risk factor is family history. If a close family member has T1D, your risk is 15 times higher. However, most people diagnosed with T1D do not have a family history.

While those with a family history of T1D present a greater risk for developing the disease, approximately 90% of people diagnosed with T1D have no family history at all.[1]

Why get screened for T1D?

While T1D cannot be prevented, early detection through autoantibody screening can help individuals to:

- Reduce risk of life-threatening complications and hospitalization
- Better plan for and manage potential diagnosis
- Potentially participate in research trials to advance management of the disease

Screening can also significantly reduce the incidence of diabetic ketoacidosis (DKA), a serious complication of T1D, among those newly diagnosed.

Where can I get screened?

There are several screening options – all done through a blood test to identify diabetes-related autoantibodies:

- **Commercial Labs:** Local commercial lab, such as LabCorp or Quest Diagnostics[2]
- **TrialNet:** TrialNet location, event or health fair – or test kit to use at home and bring to commercial labs (at no cost to relatives of people with T1D)[2]
- **Autoimmunity Screening for Kids (ASK):** Free screening available to U.S. residents aged 1+ with or without a family history of T1D – through Barbara Davis Center for Diabetes and at-home screening kits[3,4]

**This list is not complete. The organizations listed are examples and are not officially endorsed.*

What do my child's test results mean?

NEGATIVE (0-1 autoantibodies): If your child is under the age of 15, you may consider having them rescreened every year.

POSTIVE (2 or more autoantibodies): Talk to your child's healthcare provider about confirmatory testing, establishing a monitoring plan, and options for management.

How can I best manage a T1D diagnosis?

T1D can be effectively managed with the right tools and resources. If your child is newly diagnosed with T1D, talk to your healthcare provider about developing a monitoring and management plan. The plan should then be shared with your child's school nurse.

1. Sims, E.K., Besser, R.E.J., Dayan, C., Rasmussen, C.G., Greenbaum, C., Griffin, K.J., Hagopian, W., Knip, M., Long, A.E., Martin, F., Mathieu, C., Rewers, M., Steck, A.K., Wentworth, J.M., Rich, S.S., Kordonouri, O., Ziegler, A.-G., Herold,K.C. (2022). Screening for Type 1 Diabetes in the General Population: A Status Report and Perspective. Diabetes 71 (4): pp. 610–623. https://doi.org/10.2337/dbi20-0054
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3. Barbara Davis Center for Diabetes (n.d.). Autoimmunity Screening for Kids: Screening Locations. https://www.askhealth.org/locations
4. McQueen, R.B., Rasmussen, C.G., Waugh, K., Frohnert, B.I., Steck, A.K., Yu, L., Baxter, J., Rewers; M. (2020). Cost and Cost-effectiveness of Large-scale Screening for Type 1 Diabetes in Colorado. Diabetes Care 43 (7): pp. 1496–1503. https://doi.org/10.2337/dc19-2003

Online Resources for Parents/Caregivers

The Type 1 diabetes (T1D) community includes families and organizations across the United States. They work to educate and support people living with T1D.

The resources below come from trusted T1D advocacy and support groups. They offer clear, reliable information to help you learn more about Type 1 diabetes, understand screening and its benefits, explore screening options and find guidance on managing a new T1D diagnosis.

- Type 1 Diabetes (ADA)
- For Caregivers (ADA)
- Diabetes Management (Beyond Type 1)
- ADA Safe at School
- DiaTribe Type 1 Diabetes
- T1D 101 (Breakthrough T1D)
- Early Diabetes Screening & Detection (Breakthrough T1D)
- TrailNet.org

COMMUNICATING WITH PARENTS/CAREGIVERS/ COMMUNITY

Sample School Newsletter Article or Email to Parents/Caregivers About T1D and Screening Benefits

Dear Parents and Guardians,

This letter is about a serious health condition called Type 1 Diabetes (T1D). As part of our school's commitment to the health and safety of your children, here is some information regarding screening for Type 1 Diabetes (T1D).

What is T1D?

Imagine your body needs a special key to unlock cells and get the energy it needs. In people with T1D, their bodies stop making that key (called insulin). Without insulin, this means their bodies can't use the food they eat for energy. T1D is not caused by eating sugar. It cannot be prevented.

Who gets T1D?

T1D can happen to anyone, even kids. It's not something you can catch, and it's not caused by eating too much sugar. Sometimes, it runs in families.

What are the warning signs of T1D?

- Increase in thirst.
- Increase in urination.
- Bed wetting in children who did not do that before.
- Increase in hunger, even after eating.
- Unexplained weight loss.
- Feeling very tired.
- Blurry vision.
- Dry Mouth.
- Itchy or Dry Skin.
- Fruity breath.
- Dry or flushed skin.
- Feeling sick to stomach.
- Vomiting.
- Stomach pain.
- Trouble breathing.
- Confusion.

Why is early detection important?

If T1D isn't caught early, it can cause serious problems.

Screening is like a special test that can find T1D even before you feel sick.

Early detection can help people get the right care and live healthier lives.

We're here to help!

Talking with your doctor or pediatrician about screening for T1D is best. We also want to make sure you have the information you need. I invite you to stop by the school clinic to get some helpful resources about T1D and screening. Please don't hesitate to ask if you have any questions.

Sincerely,

[Your Name/School Name]

Sample Social Media Posts About T1D and Screening Benefits

Sample posts are for school nurses to post, or the school's media team to post on school platforms.

Type 1 diabetes (T1D) is a lifelong condition. It happens when the immune system attacks the cells in the pancreas that make insulin. You can't prevent T1D. Screening for T1D is a blood test to look for diabetes-related antibodies and can help families plan ahead.

Screening for Type 1 Diabetes (T1D) can help prevent serious illness like diabetic ketoacidosis (DKA). Learn more about the benefits of T1D screening at XX.

Symptoms can develop quickly. T1D can happen suddenly. Screening can help families plan. Screening can reduce the risk of serious illnesses like diabetic ketoacidosis (DKA). Learn more at XX.

#DYK the difference between Type 2 and Type 1 Diabetes? Type 1 Diabetes (T1D) is a lifelong disease that cannot be prevented. Type 2 is nothing like type 1. Learn more at XX.

#DYK that approximately 90% of people diagnosed with Type 1 Diabetes (T1D) have no family history of T1D? Early detection through screening can help you plan and manage a potential diagnosis. To learn more about screening for T1D talk to your doctor.

#DYK Type 1 Diabetes (T1D) has 3 stages? Today, most people are diagnosed in Stage 3 when symptoms appear. Screening can detect T1D earlier. Learn more at XX.

#DYK family history is the highest risk factor for developing Type 1 Diabetes (T1D)? Screening can help you plan and manage a potential diagnosis. Talk to your doctor to learn more about T1D screening or visit XX.

PART 3:
STATE T1D SCREENING RESOURCES

State T1D Screening Resources

Georgia

- Georgia Dept of Health Information for School Health: Diabetes Fact Sheet (Spanish)
- Georgia Dept of Health Information for School Health: Diabetes Fact Sheet (English)

Maryland

- Maryland Dept of Education/Maryland Dept of Health: T1D in Children: What Parents and Guardians Should Know