



How to talk to policymakers about early detection of T1D?

Across Europe, momentum is building around **early detection of type 1 diabetes (T1D)**. An increasing number of pilot projects and initiatives are demonstrating strong outcomes, alongside a growing evidence base. The challenge now is clear: how do we move beyond fragmented, project-based efforts toward sustainable, nationwide screening programmes embedded within health systems?

Engaging policymakers is critical to this transition - but it requires a strategic and well-prepared approach, supported by evidence. In a policy environment where health competes with many other priorities, clear messaging, strong alignment, and actionable proposals are essential. Below are **key considerations** to help **maximise impact** when advocating for early detection of T1D.

1

Speak with one voice.*

Policymakers face significant time constraints and competing demands. A unified message from the T1D community - bringing together clinicians, researchers, patient organisations, and industry - is much more impactful than fragmented advocacy.

Before engaging, **align on a shared vision** and define clear, common asks.

A coordinated approach signals credibility, consensus, and urgency.

*For details, see: [How to build a unified voice](#)

2

Keep the message clear and accessible.

Policymakers are not specialists in diabetes nor health. **Avoid technical jargon** and communicate in clear, relatable terms. For example, instead of "autoantibody screening", say "a simple blood test that can detect type 1 diabetes at a very early stage, before symptoms appear".

Focus on **clarity and actionability** rather than technical detail.

The goal is **understanding**, not scientific precision.



3

Build a compelling case.*

Effective policy engagement goes beyond presenting your case - it requires framing the issue in a way that **aligns** with current **policy priorities**.

Key considerations should include:

*For details, see: [Additional Practical Resources for Policymaker Engagement](#)

Public Health Impact

Early detection can prevent life-threatening diabetic ketoacidosis (DKA), reduce emergency admissions, and improve long-term health outcomes.

Complement data with **real-world examples**. For example, a simple comparison - a child diagnosed late with DKA versus one identified early - can make the issue relatable and tangible.

Economic Impact

Early diagnosis reduces avoidable hospitalisations and intensive care use, **supporting** more **efficient allocation of healthcare resources**.

Use data to support your argument, such as proportion of children presenting with DKA at diagnosis; or cost differences between emergency and early diagnosis.

Feasibility

Policymakers need reassurance that early detection is **practical and implementable**. To support your case, make sure you can demonstrate that: **(1)** Screening programmes already exist; **(2)** They can be integrated into existing healthcare pathways, and **(3)** Pilot initiatives, such as EDENT1FI, prove viability and practicality of screening.

Be **prepared to address important questions**: *Why is this important? What does it cost? Who delivers it? How does it fit into the current system? What is the overall impact of your proposal?*

For example, the European Diabetes Forum and partners developed an EDENT1FI-endorsed protocol for combined childhood screening of type 1 diabetes (T1D) and familial hypercholesterolaemia (FH) in the first decade of life. As FH screening expands across countries, this approach is more practical to implement.



4

Define your asks.

Be specific about what you are asking for. Lengthy or overly broad proposals are less likely to be taken upon. Examples of concrete asks include:

- Funding a national or regional pilot screening programme.
- Integrating early detection into national diabetes strategies.

5

Tailor your approach to the audience.

Different policymakers have different priorities. Local or regional decision-makers may focus on hospital capacity, workforce pressures, and community impact. National policymakers are more likely to prioritise cost-effectiveness, scalability, and alignment with broader health strategies. Adapting your message increases **relevance** and **effectiveness**.

6

Ensure long-term engagement.

Policy change rarely happens through a single interaction. **Building relationships** is essential. Follow up after meetings, share relevant updates, and position yourself as a trusted partner and resource. Policymakers value **recognition** for their work, and **visibility** matters to them. Involve them in events, media features, or publications to acknowledge their contributions and strengthen engagement.

7

Don't give up after the first meeting.

Advocacy is a long-term process. **Do not be discouraged if you first hear “no”** or do not receive a clear commitment. **Follow up**, address any concerns raised, and be prepared for several conversations. **Ask** what evidence, information or conditions would help them reconsider, and use this to shape your next approach. Engage multiple policymakers to build broader support for your cause.



How to build a unified voice

EUDF Recommendations

Creating a **strong, coordinated message** starts before engaging with policymakers. Below, we outline a few practical steps that can help align diverse stakeholders and ensure you speak with clarity and impact:

- **Bring the right people together**

Involve key actors across the T1D landscape, including clinicians, researchers, scientific societies, patient organizations, nurses, primary care, health economists and industry. A broad coalition strengthens credibility and ensures all perspectives are reflected.

- **Agree on a shared vision and goals**

Define a common ambition, clear priorities, and concrete objectives. Align on what success looks like and the core messages you want to deliver.

- **Define roles and coordinate efforts**

Establish a simple structure: who leads, who contributes to which topics, and how you collaborate. This helps avoid duplication and ensures consistent messaging.

- **Include the voice of lived experience**

Engage people with T1D and patient communities from the start. Their insights make your message more relevant, credible, and impactful.

- **Build on existing evidence and initiatives**

Use available data, pilot programmes, and established recommendations to support your position and demonstrate feasibility.



Additional Practical Resources for Policymaker Engagement

Questions policymakers may ask and how to answer them

Policymakers are likely to ask practical questions about the value, feasibility and impact of early detection programmes. **Being prepared with clear, concise and evidence-based responses** can help build confidence, address concerns and keep the discussion focused on actionable solutions.

- **Why should we prioritise T1D when many other health issues compete for resources?**

T1D often affects children and young people and can lead to life-threatening complications at diagnosis. Early detection helps prevent avoidable emergencies, support and educate families, and enables health systems to integrate emerging therapies and care approaches more effectively.

- **Is there evidence that screening works?**

Yes. Multiple screening initiatives and research programmes across Europe and internationally have demonstrated that early detection significantly reduces rates of diabetic ketoacidosis (DKA) at diagnosis by up to 93% and improves preparedness for the onset of clinical disease. The growing evidence base is supporting discussions on broader implementation.





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- **How can this fit into existing healthcare systems?**

Early detection does not necessarily require the creation of a completely new programme. Screening can often be integrated into existing child health visits, preventive healthcare pathways or other population screening initiatives. Examples such as combined screening approaches are already being explored.

- **Can screening for T1D be cost-effective?**

Yes. Although screening requires investment in testing, confirmation, and follow-up, costs can be reduced by integrating it into existing child health checks or routine blood tests. While further real-world evidence is still emerging, screening has been shown to reduce DKA at diagnosis by up to 93%, helping avoid emergency care and costly hospital admissions. Children identified through screening also tend to have milder disease at diagnosis and spend less time in hospital, with hospital stays being 25% shorter on average. This may contribute to better early- and long-term metabolic outcomes and reduce pressure on healthcare services. Children can also benefit from earlier education and preparation.

National pilot programmes and health-economic assessments can help identify the most efficient and sustainable implementation models.



Additional Practical Resources for Policymaker Engagement

Bringing the impact to life: examples

Data and evidence are essential, but **personal examples** can help policymakers better understand what early detection means in practice. Illustrating different diagnosis journeys can make the impact on children, families and healthcare services easier to understand.

- **Example 1) Consider two children who are developing T1D.**

Child A participates in an early detection programme. The blood test identifies early-stage T1D before symptoms appear. The family receives education, support and regular follow-up. They understand the signs to watch for and are prepared when insulin treatment becomes necessary.

Child B is not screened. T1D is only identified once severe symptoms appear. The child is admitted to hospital with diabetic ketoacidosis (DKA), a potentially life-threatening complication that often requires emergency treatment and may involve intensive care.

Both children develop T1D, but their **diagnosis journeys are very different.**

Early detection can help families avoid a medical emergency, reduce emotional distress and support better use of healthcare resources.

- **Example 2) Consider two families whose children develop T1D.**

Family A learns through an early detection programme that their child is at early-stage T1D. Over time, they receive information, support and regular follow-up. When insulin treatment eventually becomes needed, the diagnosis is expected and the family knows what steps to take.

Family B has no warning that their child is developing T1D. The diagnosis comes unexpectedly after symptoms appear, forcing the family to quickly adapt to a life-changing condition while coping with the stress and uncertainty of a new diagnosis.

In both cases, the child develops T1D. However, **early detection gives families time** to prepare, **access support** and approach the diagnosis with greater **confidence and understanding.**