Good afternoon, members of the committee and the community,

My name is Emanuele Raggi and I speak in support of the bill H8329. I am here today not as a representative of my employer, which is Brown University Health (or Brown University), but as a scientist and someone who has witnessed the devastating consequences of a system that denies terminally ill patients access to promising treatments, diagnostics, and life-saving innovations.

This bill—the Terminal Patients' Right to Try Act (H8329)—is about compassion, autonomy, and urgency. It is about giving patients the right to make their own decisions when facing terminal illness and removing the bureaucratic barriers that stand between them and potentially life-saving interventions. H8329 builds upon and expands the previously passed Neil Fachon Terminally Ill Patients' Right to Try Act (H7266).

The Urgent Need for Reform: The current system fails patients in three critical ways:

1. It moves too slowly. Drugs, biologics, and devices that have passed Phase 1 clinical trials—proven safe for human use—often remain inaccessible for years, even decades, while patients die waiting.
2. It prioritizes caution over urgency. For terminally ill patients, time is not a luxury—it is survival. Yet they are forced to navigate a labyrinth of red tape, financial ruin, and delays that cost them their lives.
3. It denies access to cutting-edge diagnostics. Thousands of patients are failed by current diagnostics with high false-negative rates, leading to preventable deaths.

The numbers are stark:

- In 2025, 618,120 Americans died of cancer.
- Only 4% of patients participate in clinical trials.
- Terminal illnesses like glioblastoma, pancreatic cancer, and triple-negative breast cancer often evade detection until it is too late.

This is not just a policy failure—it is a human tragedy.

A Real-World Example and Why This Bill Matters: Let me illustrate the practical impact of this bill with a real-world scenario: *Imagine you are a terminally ill patient in Detroit, undergoing heavy chemotherapy for stage 4 cancer. You learn about an innovative clinical trial for which you qualify both in New Hampshire and Rhode Island:*

- Under New Hampshire's Right to Try Act (HB 701):
    - You do not need to stay within state lines to establish care. You can access the trial without physically flying to New Hampshire.
    - Telehealth prescreening and remote consent allow you to complete evaluations and sign documents quickly and from home. Given your condition, this means you can start the trial almost immediately once the doctor confirms your eligibility.
    - Your spot in the trial is secured without delay.
- Under Rhode Island's current Neil Fachon Terminally Ill Patients' Rights Act:
    - None of these provisions are directly addressed. You would likely need to physically travel to Rhode Island to establish care and sign documents in person.
    - The time span between establishing care and signing documentation could take weeks, involving multiple flights or drives to the trial site.
    - The result? Your disease may progress to the point where you no longer qualify for the trial by the time you complete the process.

This example shows how H8329's provisions—telehealth prescreening, remote signing, and cross-state access—can mean the difference between life and death for terminally ill patients.

New Hampshire Led the Way—Rhode Island Can Be Next. Last year, New Hampshire passed a revolutionary Right to Try Act, HB701, setting a national precedent for compassionate, patient-centered care. Now, Rhode Island has the opportunity to become the second state in the nation to take this bold step, build and expand on the Neil Fachon

Terminally Ill Patients' Right to Try Act (H7266). This is not just about giving patients hope—it is about giving them a chance to fight for their lives. It is about ensuring that no one else has to die waiting for bureaucracy to catch up with science.

Why This Bill's Provisions Are Critical: The Terminal Patients' Right to Try Act (H8329) addresses these failures with specific, life-saving provisions:

1. Access to Investigational Drugs, Biologics, and Devices

This bill allows terminally ill patients to access investigational drugs, biologics, and diagnostic devices that have completed Phase 1 trials but are not yet FDA-approved. These treatments have already demonstrated basic safety in humans, yet patients are denied access due to bureaucratic delays.

2. Telehealth Prescreening

The bill allows healthcare providers in Rhode Island to conduct telehealth prescreenings for patients in any state or jurisdiction who have been diagnosed with a terminal illness or serious condition. This provision:

- Expands access to patients who may not be able to travel for in-person consultations.
- Reduces delays in determining eligibility for investigational treatments.
- Protects providers from regulatory action when acting in good faith.

3. Remote Signing

The bill permits remote signing of informed consent forms, witnessed by a notary public or licensed healthcare provider. This is essential because:

- Many terminally ill patients are too sick to travel to sign documents in person.
- It ensures that consent is not a barrier to accessing life-saving treatments.

4. Innovative Medical Devices for Diagnostic Use

The bill explicitly includes innovative medical devices for diagnostic purposes. This is critical because:

- Early detection saves lives. Devices that reduce false negatives can catch diseases like cancer at earlier, more treatable stages.
- Diagnostics that help us understand how cancer progresses over time are critical to improving quality of life and providing better care.
- Personalized medicine requires precision. Individualized treatments, such as gene therapies or neoantigen vaccines, rely on advanced diagnostics to tailor interventions to a patient's unique genetic profile.

5. Immunity Protections

The bill grants immunity from lawsuits for manufacturers, healthcare providers, and facilities involved in providing investigational treatments, provided:

- The patient has a terminal illness confirmed by their physician and a consulting physician.
- The patient has no comparable FDA-approved treatment options.
- The patient (or their legal guardian) has provided written informed consent.
- The provider has not engaged in willful misconduct or bad faith.

This protection is critical to encourage participation from manufacturers and providers who might otherwise avoid offering these treatments due to fear of litigation.

Safeguards to Protect Patients: While this bill expands access, it also includes strong safeguards to prevent misuse:

- Full Informed Consent: Patients must be fully informed about the risks, benefits, and uncertainties of investigational treatments.
- For innovative diagnostic devices, patients must be fully informed that the device may collect data to form images to monitor disease progression, but that its use is strictly for diagnostic purposes—not treatment.
- Transparency: Providers must disclose what is known and unknown about the treatment's efficacy and safety.

- Oversight: The bill includes provisions for state oversight to ensure ethical conduct.
- Patient Protections: Patients retain the right to withdraw consent at any time, and their participation must be voluntary and free from coercion.

A Moral Imperative: This bill is about giving patients a fighting chance. It is about recognizing that for those with terminal illnesses, the greatest risk is often doing nothing. By passing the Terminal Patients' Right to Try Act (H8329), Rhode Island can:

- Empower patients to access investigational treatments, diagnostics, and devices that have passed initial safety trials—tools that can also monitor disease progression to improve future outcomes.
- Protect physicians and innovators who act in good faith to help those in need.
- Encourage progress by allowing real-world evidence to drive faster, smarter regulatory decisions.
- Position Rhode Island as a leader in healthcare reform, attracting researchers, physicians, and patients seeking cutting-edge solutions.

A Call to Action: We cannot wait for the system to change on its own. New Hampshire has shown us the way—now it is Rhode Island's turn to lead. Rhode Island would become the second state to adopt these provisions and—to the best of my knowledge—the first in the nation to include innovative medical devices for diagnostic use, enabling the collection of critical data on disease progression to improve quality of life for all affected patients. I urge you to support the Terminal Patients' Right to Try Act (H8329). Pass this bill, and give hope to those who are fighting for every extra day, every extra moment with their loved ones.

Let H8329 be a beacon of hope for all patients who have lost hope.

Thank you and I am happy to answer any questions you may have.

Emanuele Raggi