

---

---

# ***Committee Meeting***

of

## **SENATE HEALTH, HUMAN SERVICES, AND SENIOR CITIZENS COMMITTEE**

Excerpt of scheduled Committee meeting

Senate Bill No. 2572

*(Danielle's Law: Requires certain staff working with persons with developmental disabilities or traumatic brain injury to call 9-1-1 emergency telephone service in life-threatening emergencies)*

---

---

**LOCATION:** Committee Room 1  
State House Annex  
Trenton, New Jersey

**DATE:** June 9, 2003  
10:00 a.m.

### **MEMBERS OF COMMITTEE PRESENT:**

Senator Robert W. Singer, Co-Chair  
Senator Joseph F. Vitale, Co-Chair  
Senator Diane B. Allen  
Senator Thomas H. Kean Jr.  
Senator Barbara Buono  
Senator Ronald L. Rice



### **ALSO PRESENT:**

Eleanor H. Seel  
*Office of Legislative Services  
Committee Aide*

Olga Betz  
*Senate Republican  
Committee Aide*

Aurea E. Vazquez  
*Senate Democratic  
Committee Aide*

***Meeting Recorded and Transcribed by  
The Office of Legislative Services, Public Information Office,  
Hearing Unit, State House Annex, PO 068, Trenton, New Jersey***

---

---

## TABLE OF CONTENTS

	<b><u>Page</u></b>
Assemblyman Guy R. Gregg District 24	2
Diane Gruskowski Danielle's Mother Private Citizen	3
Robin M. Turner Danielle's Aunt Private Citizen	8
Janice Roach Matthew's Mother Private Citizen	10
<b>APPENDIX:</b>	
Testimony submitted by Diane Gruskowski	1x
Testimony submitted by Robin M. Turner	7x
Testimony submitted by Janice Roach	15x
Testimony submitted by Kathy Wigfield Private Citizen	20x
Testimony submitted by Jeannette Green Private Citizen	21x

## TABLE OF CONTENTS (continued)

### APPENDIX (continued):

### Page

Testimony submitted by  
Douglas Gruskowski  
Derek Gruskowski  
Danielle's Brothers  
Private Citizens

22x

Testimony submitted by  
William Rindosh  
Danielle's Uncle  
Private Citizen

27x

Testimony submitted by  
Gary Rindosh  
Danielle's Uncle  
Private Citizen

28x

Testimony submitted by  
Mary Rindosh  
Danielle's Grandmother  
Private Citizen

29x

Testimony submitted by  
Jena Feiner  
Private Citizen

32x

Testimony submitted by  
Kathleen Malkiewicz  
Laboratory Coordinator  
Hotel, Restaurant, and Institution Management Department  
Middlesex County College

34x

Testimony submitted by  
Mary-Pat Maciolek  
Director and Assistant Professor  
Hotel, Restaurant, and Institution Management Department  
Middlesex County College

35x

**TABLE OF CONTENTS (continued)**

**APPENDIX (continued):**

**Page**

Testimony submitted by  
Sally Jankowsky  
Private Citizen

36x

Testimony submitted by  
Margaret Griscti  
Private Citizen

37x

Testimony submitted by  
Wanda Erneta  
Private Citizen

40x

rs: 1-15

*(Excerpt of meeting held before Senate Health, Human Services, and Senior Services Committee on June 9, 2003)*

**SENATOR ROBERT W. SINGER (Co-Chair):** Ladies and gentlemen, please have your seats.

We have a lot of people in the room, and I'd like to have some -- so we can hear people testify. One rule, if you have a cell phone -- it rings -- please take it outside. If you don't take it outside, you won't testify in front of the Committee.

I'm going to ask Senator Vitale to open the meeting, because his bill is up first.

Do you want to read the bill?

S-2572 is first.

MS. SEEL (Committee Aide): Danielle's Law requires certain staff working with persons with developmental disabilities or traumatic brain injuries to call 9-1-1 emergency telephone service in life-threatening emergencies.

**SENATOR JOSEPH F. VITALE (Co-Chair):** Thank you, Eleanor.

First, I just want to welcome Senator Kean as a new member. I know I share that with Senator Singer -- a new member to this Committee, replacing Senator Matheussen -- and welcome Senator Singer as the new Co-Chair to this Committee. One can only hope that his success as Co-Chair overshadows his success as a golfer. (laughter)

SENATOR SINGER: Oh, we're in trouble.

SENATOR VITALE: Welcome, both. I know it's going to be a great addition to this Committee.

I'd just like to call Assemblyman Gregg, who sponsored this bill in the Assembly, along with Robin Turner and Diane Gruskowski.

Come forward to offer some testimony.

Do we have an extra chair somewhere?

I just also want to recognize Senator Kean, who sponsored this bill along with me.

Diane and Robin are from Carteret, a community in my legislative district. We worked together closely, as did Senator Kean and Assemblyman Gregg, on trying to bring this bill before this Committee and to resolve this issue. It's very important that I know how committed you are to this bill.

Senator Kean.

SENATOR SINGER: Senator Kean, do you want to say something?

SENATOR KEAN: Thank you, Mr. Chairmen. It's a tremendous honor to be a member of this Committee. And it's also a tremendous honor that this will be the first bill I will have the opportunity to vote upon on my first day.

Thank you very much.

SENATOR RICE: You're doing better than I'm doing.

**ASSEMBLYMAN GUY R. GREGG:** Senator Vitale, members of the Committee, I want to thank you all for posting this bill and being cognizant of the fact that this bill is going to leave this Committee and simultaneously, hopefully, leave the Assembly Committee in about a half hour. So I certainly appreciate you putting this up to make it a little easier for us.

I think the testimony you're going to hear today is, probably, going to be far more compelling than anything I can say. As a former Chairman of the Regulatory Oversight Committee, these issues came to my attention a number of years ago -- that we had some serious problems in the way we deal with, what we would think, commonsense issues -- in the manner that some of our folks in our provider environments deal with life-threatening issues. And we would have thought that it was common sense, but I think that we have raised the bar in the elevation of the importance of having these folks, who are caring for our most needy individuals, know that the most important thing is the life of that individual. And they shouldn't be worried about their job security, or worrying about anything else while they're doing their job, other than the folks they're taking care of.

So I look at this piece of legislation as a message, not a threat. I look at it as a step forward in the way we deal with our most fragile individuals.

And with that, Mr. Chairman, I thank you for taking the bill on your side.

Thank you, Senator Kean, as well.

And I look forward to the testimony.

**D I A N E   G R U S K O W S K I:** Good morning, Honorable Co-Chairs Senator Vitale, Senator Singer; and Committee members.

My name is Diane Gruskowski, and I'm Danielle's mother. I am here, today, to testify on behalf of my daughter, Danielle, who tragically passed away on November 5, 2002, while in the care of Spectrum for Living, in Edison, New Jersey. The circumstances of Danielle's death are outrageous. Nine-one-

one was never called. Nine-one-one was never called. But first, I would like to let you know who my daughter Danielle was.

Danielle was developmentally disabled, non-verbal, non-ambulatory, and was diagnosed with Rett Syndrome.

Thirty-three years ago, a beautiful baby girl was born. She was loved and welcomed into the world by a family that was excited to have their first child and first grandchild. She brought joy and happiness into the hearts of many people. I loved Danielle very much. It is difficult to put into words how much Danielle meant to our family. Our family never lost sight of the privilege that God entrusted to us, to raise and care for Danielle. Our family was blessed by God, and we knew it. Danielle lived at home for 28 years, with no major health problems or serious illnesses. Danielle visited the doctor's office on a regular basis like you or I do.

At the age of 28, Danielle went to live at Spectrum for Living, in nearby Edison, in the hopes that greater independence of adult living would benefit her in positive ways. Unfortunately and tragically, this was not to be. In the group home, incidents of abuse and neglect began to mount, culminating, eventually, in her death. I had continuously voiced my concerns on a daily basis, from Day 1, with the executive director, associate executive director, supervisors, staff, nurses, and the director of the facility, and also Danielle's case manager. I got absolutely nowhere. I was told that the care she was getting was better than nothing. My precious daughter, Danielle, deserved better than that. After all, Spectrum assured me, continually, that all Danielle's needs would be met. But when I told all of them what Danielle needed, they ignored my pleas.

I found myself frustrated beyond belief. That is why I went to see my daughter at Spectrum almost every day. I was her voice, because she was non-verbal. I went to feed her, because staff was untrained. When I was there, I had to train staff. I could never just visit and enjoy my daughter's company, otherwise, she would have gone without a meal or a drink that night, or not get repositioned in her chair. Night after night at the facility, I had to bring all my concerns to their attention, such as her significant weight loss of 25 pounds, otherwise it would have gone unnoticed. When it came to Danielle, there was no staff trained in taking care of the needs and wants of my daughter, a non-verbal, helpless, defenseless child. Danielle was total-care and was continuously neglected.

The first 28 years, Danielle lived a happy and healthy life at home with her family, as compared to the horrendous care she received at Spectrum for Living. We enjoyed her hearty laughter, her giggles, her smiles. Danielle was included in all family functions, and she had a very active social life. She was on a softball team, a bowling league. She went to the prom. Danielle loved flying on planes, especially when she knew she was going to Disney World to see Mickey Mouse. Danielle was a flower girl in Aunt Robin's wedding. Danielle was a founder of the Carteret Specials, a group formed 30 years ago in Carteret to enrich the lives of special-needs children. The group is still going strong till today.

On May 18, 2003, family, friends, and legislators gathered at a dedication ceremony honoring the memory of Danielle. The dedication took place at the Carteret Library, where a plaque will hang so that Danielle's legacy

will live on. As you can see by my testimony, Danielle had a wonderful quality of life while she was in my care.

The actions leading up to her death are too much for me to comprehend. Danielle passed away at 10:18 on November 5, 2002. Danielle had difficulty breathing during the night and a reported temperature of 105 degrees on the morning of her death. Nine-one-one was never called. Nine-one-one was never called. Instead, she was taken in the group home van to the doctor's office in New Brunswick, where she arrived not breathing.

CPR was administered at the doctor's office, but by that time, it was way too late for Danielle. I arrived to see my daughter on the floor in the doctor's office with a tube down her throat. I got on the floor, and held her cold hand, and looked at her lifeless body lying there on the floor. Danielle was in distress all night, and no one assisted my daughter. I have since received documentation, with statements from staff, which verify that Danielle's cries for help were ignored.

These facilities need more training on life-threatening emergencies. An untrained caregiver cannot recognize signs of distress.

At 8 p.m. on November 4, Danielle had difficulty swallowing her liquid medication. Why wasn't 9-1-1 called? Midnight, Danielle was crying and had difficulty breathing. Why wasn't 9-1-1 called? At 4:00 a.m., again, Danielle was crying and had difficulty breathing. Why wasn't 9-1-1 called? At 7:00 a.m., Danielle had a reported temperature of 105 degrees. Why wasn't 9-1-1 called? My daughter was non-verbal, and further documentation stated that she kept rubbing her nose with the back of her hand, which was very unusual for her. She was trying to tell someone that she could not breathe. Her clothes

were wet from sweat and had to be changed twice during the night, and the caregiver attributed that to the house being warm. Did the caregiver also change the clothes of all the other clients? A statement from one of the staff indicated that the last time that she saw Danielle, she was pale and panic breathing. This was a life-threatening situation, and no one helped my daughter. What other signs were they looking for?

So who is accountable for the horrific care and disregard for my precious daughter's life?

Danielle's Law, S-2572, requires facilities and certain staff working with people with developmental disabilities or traumatic brain injury to call 9-1-1 emergency services in life-threatening emergencies. Currently, there is no penalty to the provider agency for any wrongdoing. It is simply a bad judgement call. Someone has to be held accountable for what happens to our most vulnerable population. What happened to Danielle is not an isolated incident. Danielle is one of many victims of provider agencies. I was let down, my daughter was let down. Everyone failed Danielle.

I am here today because I didn't know where else to go. There are many more Danielles out there with no one to speak for them. Please, I urge you to pass Danielle's Law, S-2572. There are many children and their families that will be forever grateful to you. One day, it may save the life of someone dear to you.

We miss Danielle very much, and Danielle will never be forgotten.

I just want to acknowledge the Family Alliance for their devotion and dedication to ensure a safe and meaningful life for our developmentally

disabled. Their hard work and dedication makes me very proud to be a member of the steering committee of the Family Alliance.

Thank you for listening to me, and God bless you.

SENATOR VITALE: Thank you.

Robin, did you want to say a few words?

**ROBIN M. TURNER:** I just wanted to thank the Committee very much. We've been in contact with all of you in giving you our pleas for help. And I appreciate that you're listening to us, and that you'll pass Danielle's Law for us, because it's needed. And there's many, many other bills that are needed to pass. And we need your help, because we can't do it alone.

We love Danielle, we miss Danielle. In Danielle's memory, we'd really like to make sure that all these kids don't suffer anymore.

So, thank you very much.

God bless you.

SENATOR VITALE: I know that this has been very difficult for you. And we've worked together over the past several months.

On a personal level, your advocacy is so vital to this legislation. And just on a personal note, I'd like to thank you for carrying forward, not just in Danielle's memory, but for all the children, the Carteret Specials and all the others throughout the state. This makes a big difference in their lives, hopefully.

Unfortunately, something -- a bill like this is necessary. It seems it's common sense that caregivers would call 9-1-1 in the event of an emergency, particularly one that was so life threatening. Some common sense would dictate that they would, but that's why it's necessary that this bill is put in place -- so that those workers in those facilities understand the gravity of the situation --

potential life-threatening difficulties, particularly with those with developmental disabilities.

You're advocacy has been terrific. It's a personal loss for you. I know how tough it is to be here today, but it's made all the difference. I just want to commend you for sticking with this and, again, for all the work you've done.

Senator Kean.

SENATOR KEAN: Thank you.

I want to echo the Chairman's comments and thank him, also, for his leadership in not only posting it, but working very, very closely, I know, with you and myself on this very important bill.

What happened to Danielle simply should never have happened, and never will happen again, we hope.

I'd like to thank both of you for educating me on this issue. (indiscernible) Municipal Building a couple months back.

I would also like to thank Assemblyman Gregg for his continued advocacy on this -- leadership in this regard, as well.

Again, as I stated earlier, it's a tremendous honor to serve on this Committee and to help advance this bill at this time.

But I know-- I think we have other testimony, as well.

SENATOR VITALE: I think we're going to limit the testimony -- if there is no one testifying in opposition to this bill--

But I just wanted to recognize, for the record, there are those, here, today, that are offering their support. They came down to testify but have submitted written testimony: Janice Roach; Vito Albanese; Kathy Wigfield;

Jeannette Green; Douglas and Derek Gruskowski are Danielle's brothers; William Rindosh, Gary Rindosh, Danielle's uncles; and Mary Rindosh; Jena Feiner; Kathleen Malkiewicz; Mary-Pat Maciolek; and Matthew Goodman; and Sally Jankowsky.

Janice Roach -- is Janice here? Janice wanted to testify -- say a few words. We call Janice up.

**JANICE ROACH:** Thank you for allowing me this opportunity to speak.

I need to also give a big, heart-felt thank you to my fellow members and co-founders of the Family Alliance for helping me to bring these urgent issues to the Legislature.

My name is Janice Roach, and I am the mother of Matthew Goodman, who died 16 months ago, after 16 months of restraint and inadequate medical attention. My son is the Matthew for whom Matthew's Law was named, another health and safety measure, which I urge you to take up also, as soon as possible.

But today I am here to talk about the impact for which a 9-1-1 call for emergency medical attention might have had on my son's short, and increasingly unhappy, life. While a 9-1-1 call would not have solved the system breakdowns that destroyed Matt's quality of life, I believe that by calling 9-1-1, at any one of several strategic points during his decline, staff could have saved his life. My loving, and much-loved, son died at the age of 14. He might still be with me, and with his younger brother and sister, today.

The New Jersey facility in which Matt lived was not unlike so many others throughout this state. The staff hired to work with people with

disabilities knew very little about how to respond to everyday challenges. When Matthew picked at his skin or dropped to the ground, as he did during times of anxiety or boredom, staff acted as if those behaviors constituted an emergency, and put him into arm restraints and a helmet, and, eventually, drugged with medication. When actual life-threatening emergencies occurred, they did not take medical action, because they were encouraged to believe that restraining Matt had somehow solved his problems.

When, after months of lying on the floor without exercise and activities, Matt's condition declined, there was no mandate that staff call for medical attention. A State-ordered medical report on the last 16 months of Matt's life was finally released several months ago. It showed that in his final weeks, Matt was found, on numerous occasions, to be cold to the touch and frequently unresponsive. Days before his death, staff noted a bloody discharge from his ears and mouth. He lost nearly one-quarter of his body weight in the last week of his young life. And still, no one called 9-1-1, or even saw fit to communicate this information to me. I only found out when I read the report on his death, so many months later. And I cried to think what he must have endured.

But it gets worse. During all this time, I had been working feverishly to find Matt a new placement where he would receive better care. Finally, my efforts paid off. I went to see him on Sunday, February 3, 2002 and whispered in his ear I was finally going to find a better place for him. Angel Flight would take us both there on Thursday. I couldn't wait to take my son there and make a new start for him. On Tuesday, February 4, the nurse at his medical facility called me on the phone and announced that she could find no

vital signs for Matthew. "Get him to a hospital," I yelled. And they did, but after packing his overnight bag, carrying him to a program van, and driving him all the way to Children's Hospital in Philadelphia, bypassing several local emergency rooms. Nine-one-one was never called. The next day, Matt died of sepsis, pneumonia, and acute respiratory distress syndrome.

There were so many times when this runaway train carrying Matt to his death could have been stopped by a simple phone call to 9-1-1. In fact, his entire 16 months of misery might have been derailed if, the very first time staff decided his situation was so dire that all they could think of was to tie his arms down and put a helmet on his head, they had called for real medical intervention instead of applying such crude measures.

Matthew's tragic case teaches us several crucial lessons about the importance of making a 9-1-1 call when facility staff are faced with a medical emergency.

Under present circumstances, program staff are failing to make these calls, even in dire situations in which lives are being lost. Why? Perhaps they fear that their supervisors will be angry or find them to have exceeded their authority. Danielle's Law will take this pressure off of staff by requiring that they make that call.

Program staff, all too often, lack sufficient knowledge of health care and make inadequate decisions when faced with a very sick individual. Average facility staff persons -- many of them with a high school education or G.E.D, or even LPN and associate degree -- should not be making independent assessments in critical situations. In fact, it is unfair to them to place them in

a situation of liability where they are outside of the range of their knowledge and ability.

To make matters worse, people with disabilities tend to have more extensive and complex physical problems than the average individual. Many tend to be chronically ill and may suffer from known or unknown pre-existing conditions. And many, if not most, people in disabilities programs and residential facilities are taking various medications which can interact in complex and unexpected ways, to precipitate arrhythmias or trigger respiratory problems. It takes years of specialized medical training and experience to evaluate what is happening in a client emergency, and the average staff person, and even the average program R.N., will lack this knowledge to make right decisions.

Many children and adults with serious disabilities cannot speak for themselves, or their speech may be halting and difficult to understand. They cannot draw attention to and explain their symptoms. Parents worry constantly about how people will respond to their non-speaking sons and daughters who can't advocate for themselves. Danielle's Law will assure that staff are on the side of safety when it comes to health care decisions.

Danielle's Law would help end the second-class health care that so many individuals with disabilities experience. This law will send a strong message about the need to get immediate medical attention for any problem that looks serious, just as we would for a non-disabled person.

On behalf of Matthew, Danielle, and countless others who are so vulnerable and so precious to us, let us send a message that common sense and

prompt medical care will prevail from now on. Please, before another life is unnecessarily lost, pass Danielle's Law today.

Thank you.

SENATOR VITALE: Thank you, Janice.

Comments from the Committee?

SENATOR SINGER: Mr. Chairman, I'd just like to say that, having been involved with Arc for 25 years -- and my nephew has Down Syndrome -- you're dealing with a very special population. And their ways of communications are not the ways that other people might communicate. And the staff must be trained to recognize that and recognize things that are not normal in their patterns of the day. That lack of training of the staff causes these kinds of serious conditions to happen.

There's no question about it, in your home, if your daughter wakes up with sweats, you're concerned, you're looking a second time, you're calling the doctor or taking her to the emergency room. This is standard procedure when we take care of our children at home. It certainly should be standard procedure of taking care of our children when they're not in our homes.

So I appreciate the fact that you took time out of your schedules to come down and share with us. I know that all of us here are sympathetic to what you're talking about, and all of us have experiences dealing with special needs children to be concerned about it.

Thank you so much.

MS. ROACH: Thank you.

MS. TURNER: Thank you.

MS. GRUSKOWSKI: Thank you.

SENATOR VITALE: Move the bill.

SENATOR KEAN: Second.

MS. SEEL: On Senate Bill 2572, Senator Rice.

SENATOR RICE: Yes.

MS. SEEL: Senator Kean.

SENATOR KEAN: Yes.

MS. SEEL: Senator Buono.

SENATOR BUONO: Yes.

MS. SEEL: Senator Vitale.

SENATOR VITALE: Yes.

MS. SEEL: Senator Singer.

SENATOR SINGER: Yes.

MS. SEEL: The bill is released.

**(MEETING CONCLUDED)**