

# The Invisible Man

*Mark Siegel's struggle to be seen and heard*

By Adam Wahlberg

All Mark Siegel wanted to do was listen to Dennis Kucinich give a speech. He didn't need special attention. He just wanted to sit and listen. Didn't happen. Story of his life.

"It was a packed house at Roosevelt Senior High School and my nurse and I were seated up front. Kucinich finishes his speech and gives me this horrible, pitying look and comes over, grabs my face in his hands, and plants a wet one on my cheek," Siegel recounts in mock horror. "I was pretty weirded out by the whole thing, but let's face it, I make a good photo-op."

"I think he just got carried away," he adds. "Either that or he was just so excited to see someone shorter than himself."

Such is one's life when spinal muscular atrophy (SMA) confines you to a wheelchair. Everywhere Siegel goes people see him as a symbol. To some he's up-from-adversity Horatio Alger. To others, he's oh-the-poor-dear Tiny Tim. He's rarely just Mark Siegel.

"People either don't see you at all or they see nothing but the chair," he explains. "They get self-conscious and don't know how to act. It's understandable. It doesn't really bother me."

I didn't feel compelled to plant a wet one on him when we met in the fall of 2002, but I admit I was unsure how to behave. He was relatively new to the downtown condominium where I live when we introduced ourselves in the elevator. It was awkward talking to him. He speaks softly and with a throaty timbre, almost as if he's under water. A ventilator regulates his breathing, which causes him to occasionally pause while forming words. I wasn't sure how conversant he could be. This uncertainty evaporated a few weeks later when he asked me to vouch for him at the polls.

On our way to and from the voting place that snowy morning, we shared memories of the late Senator Paul Wellstone — "he was one of the few politicians who wasn't condescending to disabled people," Siegel told me — and got to know each other. Turns out he's a lawyer. And a disability-rights activist. And a novelist. And a funny story-

teller. Clearly, when you look at the person and not just the chair, there is a lot to see. I wanted to learn more about him and how he lives his life. And, as is his nature, he agreed to once again serve as a symbol: that of the working disabled lawyer.

## PATHWAYS TO EMPLOYMENT

At 8:15 each weekday morning Siegel and a nurse — he requires 24-hour care — load into a specially equipped van and drive to a state Department of Human Services office in Roseville. It is here that Mark works as a policy consultant in the department's Pathways To Employment division. "We build systems that support the employment of people with disabilities," he says. "My job is varied. Some of it is analysis, some community outreach, some logistics."

Siegel spends much of his time working on the Medical Assistance for Employed People with Disabilities (MA-EPD) program — "it's Minnesota's version of Medicaid for disabled people ... it pays for services they use in their daily lives, such as personal assistance or wheelchairs," he says.

As part of his job, he gives presentations about MA-EPD and other state resources. I sit in during one at the Roseville Public Library. I assume speeches like this are difficult for him, but he gets a laugh right at the top by complaining about being cooped up in a library all afternoon, then proceeds to do 15 polished minutes. Audience members nod and smile, take notes and thank him for his visit.

It's this ability to connect with others that serves him so well in his career, says one of his close friends. "His personality always shines through in whatever situation he is in," says Laura Ferster, a lawyer at Dorsey & Whitney. "A big part of being a lawyer is the ability to put people at ease and establish a rapport, and he certainly has those skills."

He gravitates toward positions that allow him to advocate for others. His first job out of law school was at the Minnesota Justice Foundation, matching law students with public-interest volun-

teer opportunities. He then spent a year clerking for the Hon. Franklin Knoll in Hennepin County District Court before returning to advocacy at the Parent Advocacy Coalition for Educational Rights, where he counseled young disabled adults. He found his current job two years ago through an advertisement in the *Access Press*.

"This is really the perfect position for me," he says. "Not only do I strongly believe in these services, I use them. The MA-EPD program is how I pay for much of my help."

## LIVING INSIDE HIS HEAD

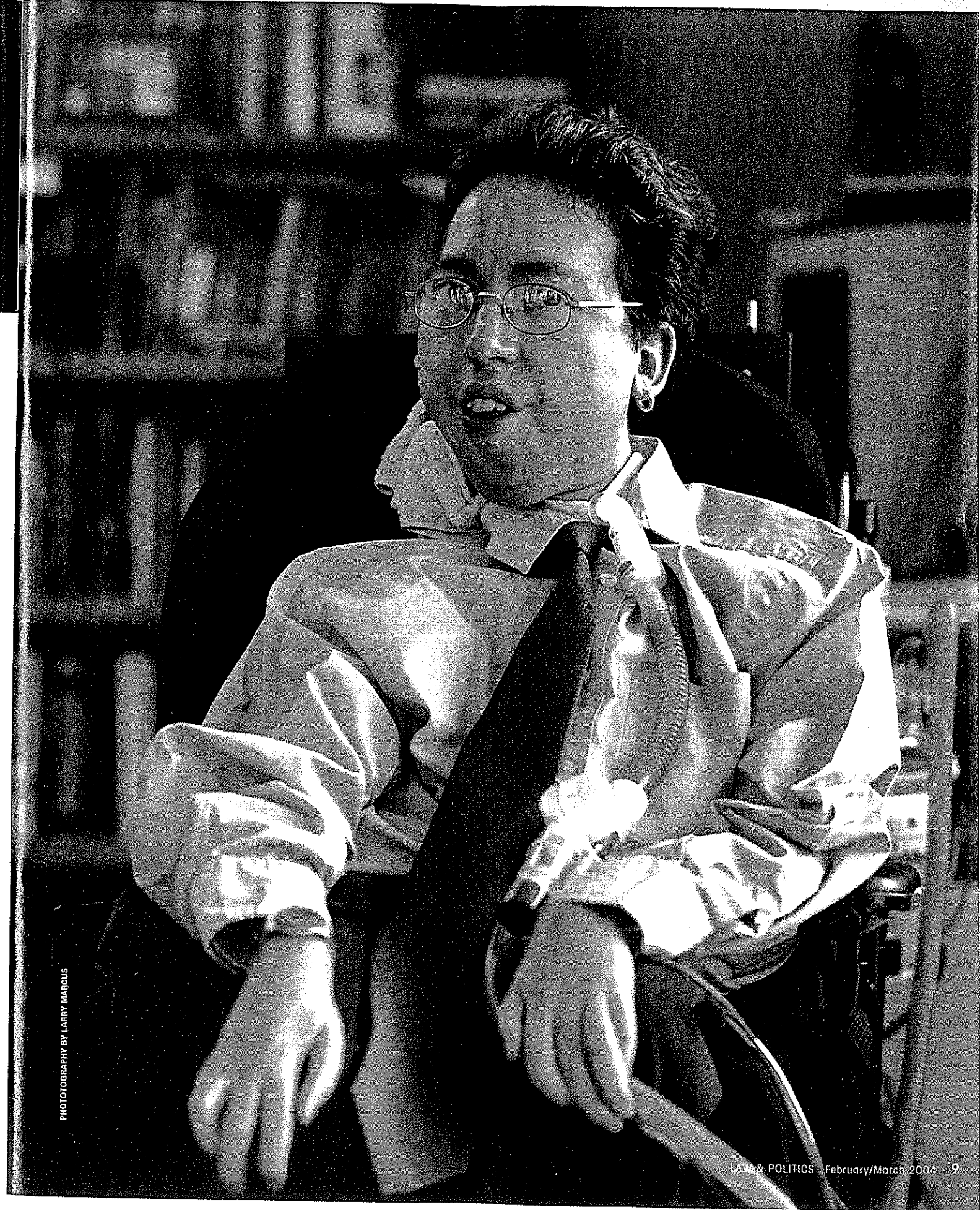
Siegel, 30, was born with SMA, a genetic condition that weakens and ultimately destroys the nerves that control voluntary movement. Unlike those with spinal injuries, he does experience normal physical sensations. And for a while he did have some control of his limbs; he could hold a pencil when he was a child. But today his range of motion is mostly limited to wiggling his thumbs and toes.

He has a normal-sized head that he keeps propped up with a folded towel, a handsome face, wavy brown hair and an earring in his left ear. His torso is quite small; he weighs only 75 pounds. He rarely eats food since chewing is difficult for him. Instead, he ingests liquid meals directly into his stomach through a gastrostomy tube, which he unabashedly shows me. "I enjoy eating, but this is just easier," he says.

Headsets help him control most of his activities. He has one to emulate the mouse on his computer, another lets him use the phone, and a third responds to verbal commands. "Most of my interaction with the world occurs via my head ... you could probably cut it off and put it in a jar a la 'Futurama' and I would still have a productive life," he laughs.

## GROWING UP IN GREEN BAY

Siegel is the oldest of three children. His mother is a retired college professor, his father a microbiologist-turned-sales consultant. He is the only member of the family with a disability.



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## Mark Siegel

He didn't exactly spend his childhood playing shortstop or building tree houses. Physically, he was underdeveloped. He spent a lot of time in the hospital. But intellectually, he thrived. Blessed with a fertile mind and a vivid imagination — he spent much of his free time writing short stories — he breezed through high school. "I was sick a lot and missed plenty of days, but I did OK in class," he says.

He enrolled at St. Norbert College, where his mother taught German, just outside his hometown of Green Bay, Wisc. (Yes, he is a Favre-loving Packers fan.) He graduated with a 3.88 GPA, earning a degree in English. After that, the law beckoned.

"I first thought about law school in high school as I saw lawyers as people who like to debate, like to use words, and that appealed to me," he says.

So he headed north to the University of Minnesota Law School. And like most first-year students, he went through a bit of a *Paper Chase* adjustment. "Law school was a shock at first ... suddenly you're surrounded by people who are just as bright, if not more so, as you are," he says. But, as always, he adapted and thrived. And after graduation his legal career unfolded logically and quietly, just the way he wanted.

Except for the time he was the subject of a state Supreme Court case that roiled the legal community.

### ALL DISABLED CLERKS OUT OF THE COURTROOM

Siegel was a star in Knoll's eyes from the day he interviewed to be a clerk. "When we got done with the standard questions, I asked him if he had any, and he said, 'What's your judicial philosophy?' [laughs]," says Knoll, who is now retired from the bench. "I had never been asked that by a law clerk interviewee. ... This indicated to me a serious thinker who is not afraid to speak his mind. Nobody in my chamber, including me, was intimidating to him in any

way, I can assure you."

Once a few adjustments were made — a desk was put on the floor of the courtroom so he wouldn't have to navigate stairs (clerks typically sit on a raised platform just below the judge's bench), an automatic door opener was added, a few computer programs were installed — Siegel was able to perform all his clerking duties.



Siegel being courted by Dennis Kucinich

"He was excellent," Knoll recalls. "He was good with the lawyers, and his legal writing was top-notch. His work was right up there with the best of the clerks I've had, and I've had about 30 through the years."

Then it came time for Siegel to staff a jury trial by himself for the first time. That's when things got complicated.

"I was clerking during a personal-injury case. The plaintiff had been run over by a school bus, and early on in the trial his attorney makes a motion to have me removed from the courtroom. His concern is the jury will see me, a disabled person with a job, and they will be less sympathetic to his client, who he is arguing is too injured to work.

"Well, the judge lets me stay. The plaintiff ends up losing and his lawyer makes a motion asking for a new trial, again saying I should have been removed from the courtroom. The judge gets ticked. He writes a letter of complaint to the Lawyers Professional Responsibility Board that ends up being appealed all the way to the state Supreme Court," he says.

To say the judge got ticked is putting it mildly. He went Tony Soprano on the guy. "Yeah, I think

PHOTO COURTESY OF MARK SIEGEL



## Mark Siegel

I was more angry than Mark over the incident," Knoll concedes. "I was just staggered by the motion. To me it was a clear case of a member of a protected class being discriminated against on the basis only of his disability. When everything was over, I felt I had an obligation under the rules of judicial conduct to report the unethical conduct."

The case made Siegel a bit of a cause celebre. The legal community polarized into those who rallied around him as a martyr of workplace inequality, and those who felt the judge had overstepped his bounds in seeking public reproach against the lawyer. Tim Maher, who was Knoll's other clerk at the time, remembers that the coolest head during the imbroglio was Siegel's. "I think he had probably dealt with similar things before and this was just more of the same. He didn't let it faze him."

"What was kind of funny was when Mark got to the hearing at the Supreme Court courtroom in the Capitol building, he wasn't able to enter because it wasn't

accessible [he had to set up one of his own ramps to get in]. Accessibility is something Mark takes seriously," Maher adds, "but I think he appreciated the irony."

The Supreme Court ultimately decided that while the lawyer's actions were worthy of admonishment, they were isolated and of a non-serious nature. In other words, the lawyer was reprimanded, but not as severely as the judge would have liked.

"I respect the members of the court, but I disagree with their reasoning and with the outcome," says Knoll. "I thought the court should have made a stronger statement that this was inappropriate."

To this day Siegel seems unruffled about the whole affair. It's clearly not his favorite subject, and he dismisses questions about it with a "whaddya gonna do?" look. But, after some prodding, he does say, "Disability discrimination is still not considered as serious as racial or gender discrimination, which is unfortunate."



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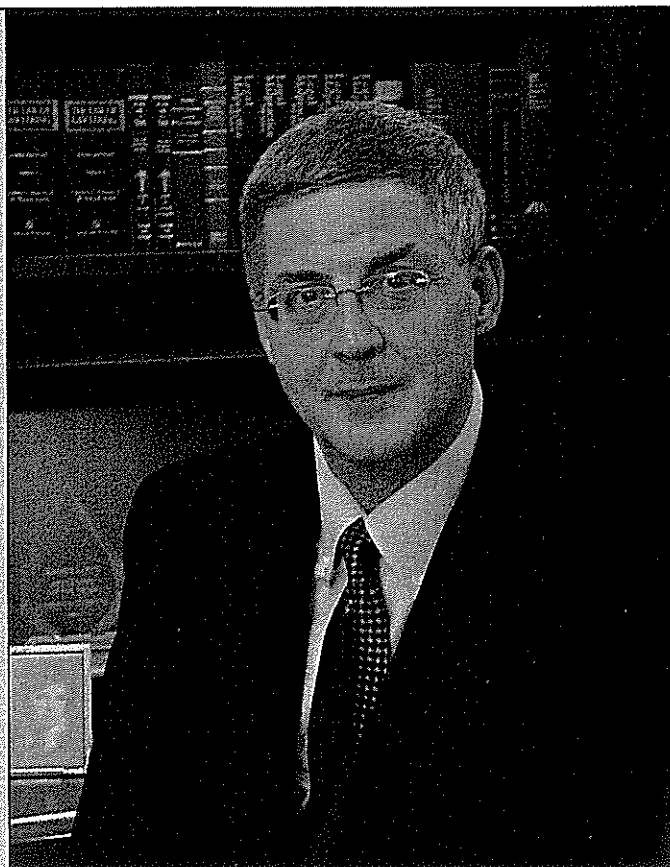
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## Mark Siegel

### THE 19TH FLOOR

If Siegel is reluctant to get on his soapbox in conversation, there is one place he doesn't hold back: The 19th Floor. This is his daily blog that he's maintained since the summer of 2002 (named for the floor he lives on in our building). He comments on any topic on his mind that day, from movies (he loved *Kill Bill*) to politics (he doesn't love Dubya). He notes in one of his first posts, "My reason for blogging is simple: In a life where I have to depend on others for everything, writing is one thing that I can do independently."

than Siegel. Just ask those who know him best.

"There are two things he doesn't like," says Maher. "He doesn't like to be called a role model, and he doesn't like to be called an inspiration."

Knoll concurs. "I remember I once referred to him as a role model and he just got madder than hell at me," he recalls, with a laugh. "He let me know in no uncertain terms that he doesn't want to be characterized in that way."

Yet the special recognition keeps coming. For instance, last year Siegel was given an award by

"I once referred to him as a role model and he just got madder than hell at me," says Judge Franklin Knoll. "He doesn't want to be characterized in that way."

He continues, "Many of the Anonymous You have probably never met someone with a disability. By reading my stuff, you get a little peek into a life that's at once very similar and very different from your own life. You may read this site and feel amusement, puzzlement, voyeuristic fascination, or even pity. I have no idea. I just hope to give people some other views on disability that have nothing to do with a telethon or a human interest story on the news."

The site is only one of his many literary pursuits. He recently completed a coming-of-age novel, which he is hoping to get published, and is now working on a comic strip that features a superhero in a wheelchair. That's some prodigious output, especially for a guy who writes by clicking a remote-control device with his right thumb. "It's not a fast process," he admits, estimating that he taps out about 15 words a minute, "but I really enjoy it."

the Courage Center for his contributions as a disabled person in the workplace. He enjoys the recognition of such awards but takes them with a grain of salt. "It was nice, but I remember thinking that I'm only 29. I'm just getting started, and I'm already getting an award? It seemed a bit odd," he says.

It is odd. Well-intentioned, but who else gets an award for essentially just living his life? It's enough to question one's place in society. What is he if not the image in someone else's mind of a man in a wheelchair? Strip away all the kudos and the legal battles and the maulings by politicians and what is left? It's a question Siegel ponders often, and addresses in a poem he wrote and posted on his Web site. It's vivid and melancholy and funny and brimming with life. It's Mark.

### FLAME

Looking at me,  
I'm not much.

The body that curses

And twists like a slow river.

The voice indistinct and muted,

Barely heard at a dinner party.

The plastic tube disappearing into

The hollow of my neck.

### DON'T CALL HIM AN INSPIRATION

It is safe to say that nobody since Charles Barkley wears the title of role model more reluctantly

## Mark Siegel

I'm the All-American Superhero  
I'm the Invisible Man.  
I'm the Circus Freak.

I'm like a forgotten flame,  
Burning quietly in someone's  
hearth.

At time, I'm little more than an  
ember  
Lying among the ashes.  
And I need the breath of  
another to give me life.

Other times, I'm a forest fire,  
Powerful and cunning and fast,  
Scorching the earth while old men

Sleep in distant watchtowers.  
For now,  
I'm content to sit on the end  
Of your candle, flickering  
In the night breeze and casting  
A ribbon of shadow across  
your sleeping face.

And I'll still be burning when  
you rise with the sun,  
The light coming through the  
window and  
Streaming through your hair. L&P

— Check out Siegel's Web site at  
[www.the19thfloor.net](http://www.the19thfloor.net)

### Siegel in His Own Words

*The 19th Floor: October 05, 2002 — Yes, My Date Went Very Well*

A word on disability and relationships. As many people with disabilities will tell you, society tends to perceive us as asexual beings. We're seen as either too sick or too "different" to ever experience attraction, romance, sex, etc. Of course, this is bullsh—. But we spend many a Friday night alone because the idea that we're not desirable has become somewhat ingrained. And you start feeling a bit like an outsider to the human race; like everyone else got invited to a long, great party and you're still checking the mailbox for an invitation. So when someone comes along and tells you you're kinda cool, it's something unique and just a bit wondrous.

*THE 19TH FLOOR: SEPTEMBER 20, 2003 — IN MY SOLITUDE*

Just saw *American Splendor* tonight. A remarkably funny yet sad movie. I saw aspects of my own life in those of the characters. There's a sequence where the real Harvey Pekar and his friend Toby are discussing how they cope with the loneliness in their lives. And I started to think about how I deal with my own loneliness. By reading. By watching television. By

writing things like this blog. And maybe I look to my nurses too much for companionship. It's not like I don't have friends, but most of them have families now and I don't see them much. When I was interviewing for new nurses this summer, I deliberately looked for people who I thought I'd like hanging out with. I went out with one of them tonight and it is nice to have people who I enjoy spending time with. But they are, after all, paid to be my friends. And this is probably how the rest of my life will be. While it's not the life I would have chosen had I any say in the matter, it's still sweet and I wouldn't trade it for anything.

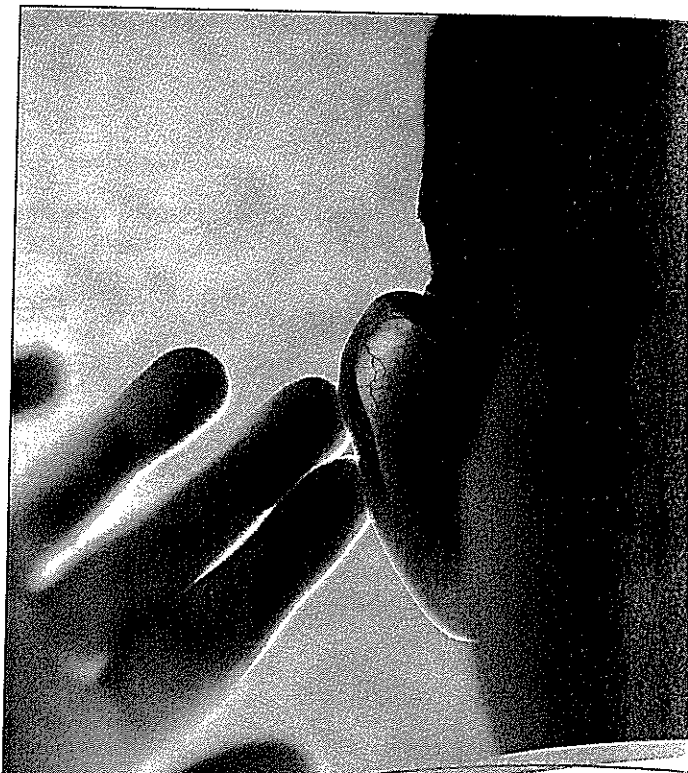
*THE 19TH FLOOR: JULY 30, 2003 — CRYPTO*

Here's another blog, written by a woman with spinal muscular atrophy (SMA):  
[www.dalqe.com](http://www.dalqe.com)

Don't tell anyone, but all these blogs by people with SMA are just a front for us to exchange coded messages regarding the upcoming revolution.

Which reminds me: *Attention all points: The three-footed lion sleeps on a bed of roses. I repeat: the three-footed lion sleeps on a bed of roses.*

Back to your regularly scheduled program...



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