

# Don't mess with Désirée

Eleven-year-old AIDS activist Désirée Stogdell has already made her mark. **By Bruce Mirken**

**A**IDS ACTIVIST GROUPS, for better or worse, have tended to attract mostly gay men. So when Terry and Désirée Stogdell first walked into an ACT UP—Golden Gate meeting last winter, the 32-year-old heterosexual hemophiliac and his 11-year-old daughter didn't exactly blend in with the crowd. That night the two helped set in motion the slow, tentative process of bridging the gulf between hemophiliacs affected by HIV and the largely gay AIDS activist and advocacy community.

The meeting also introduced ACT UP—Golden Gate to its youngest member, a kid who has turned upside down many of the adult activists' preconceptions about children. "Désirée has grit," observes longtime ACT UP—Golden Gate member Kate Krauss, who recently moved to Philadelphia. "She's charming, very bright, and very funny, but she's a committed activist.... She's a very serious person and has a very serious understanding of these issues."

"She's an active member of ACT UP—Golden Gate," Krauss continues. "She initiates projects. She's a whip when it comes to follow-up. I get calls from this little tiny voice saying, 'Kate, I'm trying to fax you the media list but I can't get through.' She's the only 11-year-old I know who has a Day Timer."

Spending time with Désirée, it quickly becomes apparent that Krauss isn't just making this up. In fact, Désirée was an activist before she ever set foot in an ACT UP meeting.

The elder Stogdell (who is divorced and has sole custody of his daughter) was always honest with Désirée about having HIV and eventually full-blown AIDS, first telling her about it when she was four. "I pretty much understood it at five," Désirée recalls. "Cause Dad didn't

really hide anything from me. He told me everything there really was for me to know about AIDS, and the more he found out the more he told me."

But not everyone at Turner Elementary School in Antioch—a town not known as a bastion of AIDS awareness—was so knowledgeable or understanding. Désirée was on the receiving end of some name-calling directed at both her and her father, but says "it really wasn't that big of a problem.... Pretty soon I made friends with the people and told them my dad has AIDS, and they kind of stuck

up for me. Nobody really makes fun of me now because my friends back me up."

But it was clear to Désirée that her classmates didn't know enough about HIV or AIDS, and they weren't getting information from the school.

"Since the end of third grade I've been bugging them for AIDS education," she recalls, but at first her efforts weren't taken seriously. "They just kind of looked at me weird," she says, "or just gave me the runaround.... They kind of looked at me like 'You don't know what you're talking about,' and some of the staff would look at me like, 'Why are you doing this? Why is this little girl coming up and asking for AIDS education?'"

"And some of them would get upset," she continues. One school staffer said "You shouldn't be talking about this," that I should get out of the office, and if I really wanted to talk about it I should say it to my principal. And my principal just went 'Uh-huh, OK,' and didn't do anything."

But Désirée Stogdell is nothing if not persistent. "I kept on pushing and

pushing, and my friends helped me too," she says. It took more than two years, but finally, at least in part because of her efforts, things have begun to change. "They finally set up this new program called Operation Awareness," she says. "They just started it this year. Fifth graders were supposed to learn about safe sex and AIDS and stuff."

But the young activist isn't satisfied yet. Although teachers were given a binder of curriculum materials by the district that included HIV and AIDS information, some teachers barely touched it and seemed to go out of their way to avoid dealing with the subject. "They could never do anything about AIDS, which is kind of funny," Désirée says, with the cynical edge one hears in the voices of adult AIDS activists who have gotten the runaround from one too many bureaucrats. "They can do more."

Désirée notes that Antioch middle schools, including Park Middle School, where she is now starting classes, "are really good about educating about AIDS," but she still thinks

comprehensive AIDS education should start at a younger age. "I think some kids get really active when they just begin middle school. Some kids don't, but some kids do. I think before they're sexually active, get 'em aware."

And she has no patience for the argument that early AIDS education promotes sex, dismissing the idea as "an excuse to avoid a problem" school administrators are afraid to deal with.

meetings of the Northern California Hemophilia Foundation (he just resigned to protest the group's acceptance of financial support from companies that manufacture blood clotting factor used by hemophiliacs) and calls those meetings "s-o-o-o boring. They get nothing done." ACT UP members, in contrast, "actually want to get out of their seats and do something. I really love that."

Being the only kid in the room

of the ACT UP—Golden Gate delegation at the recent International AIDS Conference in Vancouver, and she showed the same sort of take-charge attitude there. One night, when this reporter visited the ACT UP office in Vancouver, Désirée smiled and said, "You're lucky you got here now. This place was a mess!" So had she straightened it up? "I just sort of took over," she smiled.

Désirée and her father took part in most of the protests during the conference but were the stars of the last day's demonstration: a presentation of a Golden Urn award to Bayer Pharmaceuticals, one of several companies that sold HIV-tainted clotting factor to hemophiliacs during the '80s.

Unlike the noisy protests that had preceded it, this was a silent march through the exhibit hall, the quiet punctuated only by a slow drumbeat and the eerie sound of the marchers slapping "blood money" in their palms. Désirée, holding the urn, stood in front of a banner reading "Greed = Death," then led the slow procession through the conference ex-

hibit hall, ending in the center room. A circular banner with names of all the companies that sold tainted blood products was the ground, and Désirée placed the urn in the center.

She then joined the others in as her father spoke. "Plasmatoners have created a capitalist by knowingly selling tainted products," he declared. "Now, selling us therapies for HIV... believes it can buy off hemophiliacs funding our nonprofit organization Bayer's blood money will in place the lives lost. We can't buy it."


The emotion is obvious in Stogdell's voice when he speaks his daughter. "I was so proud at the conference, he says, especially when her picture appeared in the official conference newspaper *Daily Progress*. "Everywhere I'd pick one up and show it and say, 'That's my daughter, she's the best!'"

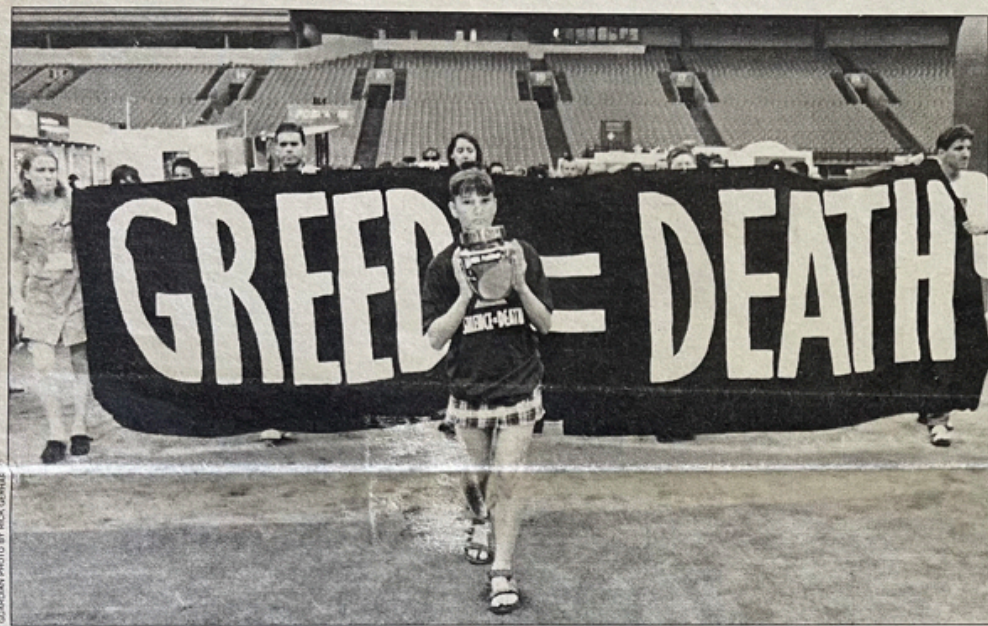
He is equally happy about activist connections. "He's coming out of the woodwork because of his participation in our cover protests," he says. "I did a talk show and said I thought hemophilia community was huge. I've gotten more support ACT UP than I've ever gotten my own community in 10 years."

But there is plenty of pain in this father-daughter relationship. Désirée cries sometimes at the possibility of her father dying. "I've been crying a lot lately," she says with a steady determination. "I cry in front of my dad every time he sees anybody else cry. T-cells already go down.... I'm most like two peas in a pod—ever he's sad, I'm sad, and vice versa. I'm sad, he's sad. So if I'm in front of him I know it's to make Dad feel guilty and

The adult members of ACT UP worry about her sometime have to be careful not to exploit her. "I observe Krauss, who frets a lot about adult responsibilities that has sometimes had to take over," she says.

But Désirée coolly observes that she's a really tough fighter. "It makes it even tougher when a child involved. I think we have enough demos [at the conference]. The more demos the more the cameras will picture and the more the point across. I take advantage of it in a good way."

Indeed, the pharmaceutical industry might do well to learn from Désirée and her father. "I'm a student and teacher in Antioch. I'm around her school, the way she says with a smile, is "Don't mess with Désirée." 



**And a child shall lead them:** "The more demos we do, the more the cameras will get my picture, and the more the point will get across."

*I personally think a lot. I even think while listening to music. Most of my thinking is usually about my future, my life's ups and downs. But there is one down that makes me cry, and that is about my dad, and why does there have to be an AIDS virus and other bad diseases. But I realized that's just LIFE.*

*Every minute with my father is priceless. Knowing that silently he is dying is hurting me inside. I wish I could just put him asleep and he wouldn't wake up. This way I would know that he is not suffering in pain, and is in peace with himself. But to be witnessing it can be even worse. But I can make a difference by trying my hardest to find a cure, or make the best of things.*

from "Living With a Person With HIV," a booklet by Désirée Stogdell

Désirée seems right at home at ACT UP—Golden Gate meetings—making suggestions, speaking about issues that come up for discussion, and generally acting just like the grown-ups. "I like it a lot," she says. "I think it's so much fun." She has frequently joined her father at board

meetings. "It makes me feel better," she says. "It lets me know that I'm more ahead for my age, and it makes me feel great because I know that I've made a big step, and now that I've made this step other kids might follow."

Désirée and her father were part



**Name of the father:** Terry and Désirée Stogdell protest at the Vancouver AIDS conference.