

A Friend in Need

Battling the rare and deadly genetic disease A-T, 13-year-old Joe Kindregan finds a pal in Ben Affleck

Her children had always enjoyed movies, so Suzi Kindregan thought it would be a treat for them to see one being made. One afternoon in August 1998 she gathered up Stacy and Joe, then 15 and 10, and headed to Dulles International Airport, about 10 miles from their Springfield, VA, home, where Sandra Bullock and Ben Affleck were filming the romantic comedy *Forces of Nature*. The Kindregans hadn't been watching long when Affleck glanced at the crowd and saw Joe in his electric wheelchair. "Ben was asking about the chair and playing with the joystick on it," says Suzi, 43, who watched in amazement as her son began to joke with the screen star. "Joe and Ben just bonded."

That chance beginning led to an unlikely friendship as well as a special crusade. Moved by Joe's plight, Affleck joined the fight to find a cure for ataxia-telangiectasia, also known as



"As Joe enters adolescence, he is becoming more dependent on those around him," says Affleck (at the U.S. Senate hearing).

A-T, a rare but deadly genetic disease that currently afflicts about 600 U.S. children, causing neurological deterioration and usually proving fatal by their 20s. "It seems particularly unfair," says Affleck, who recently lobbied Congress for funding for A-T research, "when something happens to a kid who hasn't had the chance to experience life yet."

Born in 1988 to Suzi, then a legal administrator, and her husband, Tom, 43, an

airline computer technician, Joe seemed a normal, healthy baby. But within a year Suzi says she noticed he was unusually "wobbly" when he started walking, and at 18 months he struggled at times to hold up his head. Misdiagnosed with mild cerebral palsy, Joe participated in sports as a kindergartner, but only with difficulty. "He was always on the wrong end of the soccer field," Suzi recalls. "And he had a hard time balancing during karate."

After he tripped and broke an arm at 7, Suzi and Tom grew increasingly concerned. Other doctors directed them to a geneticist, who in January 1996 told them that Joe's problems stemmed from A-T, which can cause trouble swallowing, slurred speech and gradual loss of muscle control. Blood tests confirmed the diagnosis. "It was devastating," says Suzi. "It was one of the darkest, worst days."

Desperate for emotional support, Joe's parents connected with 115 families in a national advocacy network called the A-T Children's Project. They also entered Joe in drug trials targeting the disease at Baltimore's Johns Hopkins Medical Center. Sadly, these didn't help, and Joe's disease quickly advanced, so affecting his mobility that he was in a wheelchair by June of 1998.



I can't tell you how much Ben has meant to Joe," says Suzi Kindregan (at home with Joe, husband Tom, daughter Stacy and dog Max).



"This drains you," Affleck (with Joe in Washington, D.C., on July 11) says of his friend's disease, "But Joe doesn't seem to resent it."

It was two months later that Joe's sister Stacy read about the *Forces of Nature* shoot and told her mother. Then came the meeting with Affleck. Almost from the moment he and Joe first talked, the actor was impressed by the boy's positive attitude. "He is a pretty together guy and very inspiring," says Affleck. After Stacy e-mailed him to say how much her brother had enjoyed meeting him, the Make-A-Wish Foundation flew the family to Los Angeles for the *Forces of Nature* premier, where they schmoozed with the stars. ("Sandy was really taken by Joe," Affleck says of costar Bullock.) Last spring, Affleck invited the family to Hawaii for the premiere of *Pearl Harbor*.

Meanwhile the friendship between the boy and the actor quietly blossomed in e-mails and phone calls. "We talk about his sister and what movies he's watching -- just normal stuff," says Affleck, who sent Joe a portable DVD player for Christmas. (Joe sent him a computer mouse pad with his photo.) And the relationship has given the seventh grader a close-up look at fame. "It's very nerve-racking being famous," says Joe. "But I'd like the girls."

Affleck says he tries to see Joe as "a regular kid." Yet he is only too aware of the difficulties the boy faces. Though he has avoided serious illness recently, Joe uses a feeding tube and shows signs of gradual deterioration. "Where Joe and I used to carry on a conversation, his mom now has to translate more because his speech has been affected," says Affleck.

The two sat side by side at a July 11 hearing in Washington, D.C., where Affleck asked senators to support stem-cell research -- which might provide a cure for A-T and other neurological disorders -- and to double the budget of the National Institutes of Health, earmarking a bigger slice for A-T research. That evening Ben and Joe were hanging out like old friends at a gala A-T fund-raiser when Affleck, who won a screen-writing Oscar in 1998 for *Good Will Hunting*, was asked whether Joe's story might be a moving subject for the screen. "Sure, I've thought of it," said Affleck, "I'm waiting for a happy ending."

- **Thomas Fields-Meyer**
- **Jane Sims Podesta** in Washington, D.C.

For more information on A-T, go to www.atcp.org
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