

Linked by Love

by C.C. Birt

Life handed her a very serious illness at the tender age of fifteen...she responded by turning that illness into a way of helping others.

Her story is an inspiring one. As the former Rutgers University student Puts it, she's seen the best of life and the worst of life.

Her name is Roxanne Black, founder of Long Distance Love. A non-Profit organization that helps bring People together from all over the world and allows them to communicate with others who have similar health problems.

By providing a friend who has faced many of the same obstacles, Long Distance Love helps to alleviate the devastation caused by illness. Black says, that ultimately these friendships help people concentrate on their abilities rather than dwell on the Problems of coping with a serious illness or disability.

The program links participants by age, health problems, involvements and effects, tests and surgeries. It also tries to pair them by Personal background as well as hobbies and interests. Long Distance Love has assisted more than 2,800 People, nationally and internationally over the past five years.

Family members and friends are also encouraged to participate through a separate networking system that was recently started.

Those involved, communicate with one another by writing, calling, or talking on a cassette or video tap, using e-mail and even through art.

Black's story started eight years ago when she was diagnosed with lupus, a chronic disorder of the immune system that can cause inflammation of skin, joints, and kidneys.

At first, the diagnosis was absolutely devastating. "When you're a teenager and you're healthy, you don't think of hospitals or of being sick." "I guess you just take things for granted." says Black.

During her teen-age years when most of her friends were going to the prom, Black was faced with swollen ankles, a rash, chest and back pains, and a puffy

Then her kidneys began to fail, and she could hardly walk. That's when her oldest sister came to the rescue by donating her kidney.

"I have the best kidney in the world--I have my sister's kidney" she says.

Despite all these hurdles, after a period of mourning, she realized she could not go through her illness without



Roxanne Black—founder of Long Distance Love

something good coming out of it.

In spite of the support she received from family and friends, Black felt that the one thing that seemed to be lacking, was a relationship with another teenager who was going through the same thing.

Her initial efforts to find another teenager with lupus in her home town were fruitless; but a small article in USA Today really got the ball rolling, and Black started receiving letters of interest from all over the world...thus began Long Distance Love.

For 19-year-old Sharon, it means she doesn't have to face her isolation alone. The Florham Park, New Jersey, resident has chronic fatigue syndrome and spends most of her day sleeping.

Long Distance Love connected her with a Pen pal in Ohio who has chronic respiratory problems.

"When you're sick, you end up so cut off from the rest of the world," Sharon says. With Long Distance Love "You don't have to face it alone."

Twenty-four-year-old Sal of Coral Springs, Florida, has muscular dystrophy; but he knows his friend Jennie of

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On the Job

I have diabetes and there's a chance I might be laid off. Will I be able to find another job without being discriminated against because of my disability?

I take shots twice a day and I monitor my blood. Occasionally, I have to leave for doctor's appointments ... I know employers are not supposed to discriminate, but a lot of them do in the real world.

—Concerned in Rochester

You raise an interesting question.

When I asked lawyer Steven V. Modica of the Rochester law firm Dolin & Modica about your situation, he said it is illegal under the Americans With Disabilities Act for any employer to inquire about a job seeker's disabilities in the application process.

An employer also can't deny you a job because of concerns that your disability will cost more in medical claims. The only issue for the employer is whether you can do the job, Modica said.

"The focus is on the duties of the job and whether the individual can perform them."

It can be tough to prove you were discriminated against in the application process, Modica said, because employers often have several qualified applicants and "courts are hesitant to substitute their judgment for the judgment of the employer."

The tricky question here is whether to tell the employer upfront about the disability or wait until after the job is offered, Modica says. "The concern is **that** you're viewed differently, once you say that you have a disability."

The ADA requires people to disclose disabilities only if they need accommodations in the workplace, he said.

Diabetes is a "hidden disability" that will not be obvious to a future employer, Modica explained. So you'll need to carefully evaluate the job requirements, your ability to do the work and whether you would need assistance.

"If you realistically feel you need an accommodation to be successful in the job, it's only fair to request it in the job application.

If, for example, the employer says you have to work a night shift, and you need to take shots or frequent snack breaks during work, then you probably should discuss it.

But it might not be necessary at all. "Many folks with diabetes may not need an accommodation," Modica said. "My sense is if you don't need anything to be successful, the safest course is not to disclose it. Sometimes employers make incorrect assumptions about what a person with disabilities can or can't do. "The person with the disability is the expert," he said. "The onus is on you—what do you need to be successful?"

If an offer is made, and it's conditional upon completion of

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Love Network

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Joshua Tree, California, who has multiple sclerosis, understands the feeling he's describing when he says he's tired or weak--a feeling that other friends may be sympathetic towards but never really comprehend. Sal says, "Unless you experience it yourself, you don't know what it's like."

Long Distance Love began on a small scale out of Roxanne Black's dorm room, during her freshman year at college.

The real break came in 1993 when Johnson & Johnson Corporation, which is headquartered in New Brunswick, NJ, gave her a grant to establish an office and provided funding for a whole year.

Long Distance Love is now housed in a 1600-square foot office next door to Rutgers University. The close proximity

of the school allows Black to tap into the student internship Program.

If you should meet Black today, you would see a healthy woman who tries to eat right and works out five times a week. Her lupus has subsided. But once again she is faced with a hurdle in her life. This time it's funding. She is currently writing a grant proposal in an effort to continue to fund her organization.

Black has never received pay for her work. But her efforts have not gone unnoticed.

In October 1990 President George Bush named her his 268th Daily Point of Light. Black has also been recognized with more than two dozen awards.

In a statement released by The White House, Office of the Press Secretary, it said, "Roxanne has shown hundreds of individuals that they no longer need to fight their battles against illness alone." A feeling, Julie of Rockland County, New York, understands.

Julie has lupus, but she says her pen pal, Helen, in England, understands everything she's going through. "She can sympathize 100% with me and I can with her," Julie says.

Helen has lupus, too.

Julie says Long Distance Love is

an open line to meet people who can understand you, support you, and love

Roxanne Black puts it a little bit differently. Long Distance Love is "really like living a dream," a dream to help others and ultimately, help herself, she says.

Black says that's the key "If People can find a way to help others or find something good in their illness, they can help themselves."

Getting Connected with Long Distance Love

If you have an illness or health problem or someone in your family does, just send a self-addressed, stamped envelope for more information to: Long Distance Love, P.O. Box 114, New Brunswick, NJ 08903.

Please specify if you or your family member is the patient so the correct forms can be mailed back to you.

If you decide to get involved with Long Distance Love, you will be charged a nominal fee of \$10.00 to help cover expenses. You will then begin receiving a copy of the semi-annual news letter. Founder Roxanne Black says that fee will be waived if necessary.

Please note that the organization is not intended for romantic purposes but for support purposes. ♪

On the job

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a physical examination, then the company can ask questions about the disability. In that case, you might bring along material about your condition and explain that it won't interfere with your work.

Modica encourages job-seekers to help educate employers. "You'd be surprised how few people know what diabetes is, that it's a condition that can be controlled."

His other suggestions -

- If you're concerned about discrimination, jot down notes after the interview. This will keep important point, fresh in your mind, if you need them later.

- If you have received an offer, contingent on passing a company medical examination, consider bringing a letter from your physician showing that you've managed the disease well in the past.

- If you need to go to doctors' appointments, it's wise to schedule them during off hours if possible. ♪

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Prudential is for everyone

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diverse workforce. "We haven't seen any increase in our cost-per-hire," said Jones. "We're more effectively using our workforce because we're putting people in jobs where their skills really are, and where they can grow the most."

"The person is being hired because they have an ability that can benefit the company, they're not being hired because they have a disability," Ingber added.

Jones said, The Prudential looks for ways to make small changes, to allow those with disabilities to contribute the best way they possibly can to the company. She also recommends that other companies try a

more pro-active approach to hiring people with disabilities. "Just give it a try. Open your doors and minds to hiring people with disabilities, and not just because it's the right thing to do, but because it makes good business sense."

The Prudential has made a conscious effort to promote disability awareness and provide an environment in which those with disabilities can excel both personally and professionally. The ADA can force companies to put in ramps and provide for "reasonable accommodations," but it is companies like The Prudential that really show how diversity has improved the company and the people who are part of it. ♪