



Patients Fighting Diseases

Their New Lifeline

How sharing experiences online helps them *A4-6*



See them tell their stories in a video at newsday.com



FIGHTING DISEASES ONLINE

Network

Patients, families
find comfort and
support by sharing
stories on Internet

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When Amanda Marsh was diagnosed with non-Hodgkin's lymphoma at 22, she sought refuge and comfort in the things that allowed her to live outside her hospital room: the building's dial-up Internet, the blog she kept, and her readers who became like a family.

The cancer diagnosis and monthslong stay in the hospital drove the Islip resident online, where she chronicled her treatment, posted pictures of her bald head, and traded stories with other young people whose bodies were also ravaged by cancer at AmandaMarsh.me. "Knowing that I had these friends responding to me, that kept me going," Marsh said.

A study says she is part of a number of people — many young adults — suffering from life-threatening and chronic illnesses who turn to the Internet to trade stories, find fellow patients, and participate in emotional support groups. Many also seek medical advice, look up specific diseases, and research drug options on websites and through online discussions.

On Long Island, there are many stories: the mother who blogs of her child's ongoing battle with brain cancer, the young woman who celebrates her remission online, and the cancer survivor who says Facebook is her lifeline.

Researchers found that people with chronic diseases who have use of the Internet are more likely to blog and participate in health discussions than healthy adults, according to a study released in March by the Pew Internet & American Life Project and the California HealthCare Foundation.

It found that the majority of people with these diseases, 62 percent, use the Internet, and 51 percent of people with chronic illnesses say they have looked online for health topics. Many also see the Internet as a social tool to help them deal with personal issues and health problems. However, patients and doctors caution that while helpful, the Internet can also be filled with errors and is no substitute for personal contact.

On Long Island, many people write blogs and engage in group discussions. Others talk about the newest treatment options. Some, like Cyndy Sotomayor, 39, of North Babylon, who was diagnosed with non-Hodgkin's lymphoma in September 2007, go even

See ONLINE on A6

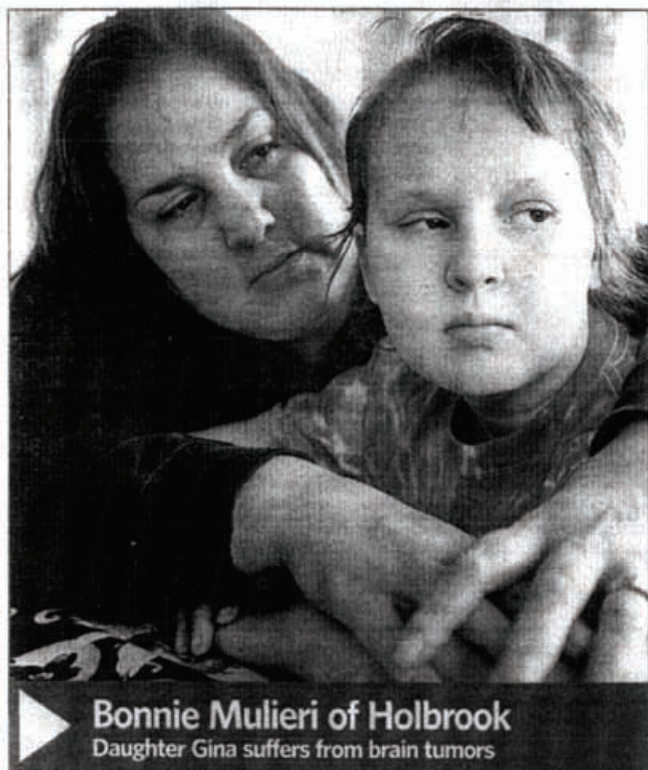


Amanda Marsh

Non-Hodgkin's lymphoma survivor; chronicled her experience online at amandamarsh.me, including posting pictures of her bald head after treatment



of care for Llers



Bonnie Mulieri of Holbrook
Daughter Gina suffers from brain tumors

For one Holbrook mother, hope comes in writing.

"I'm cried out. I think. I want Gina fixed. No more cancer. I'm done — I'm tired and I'm cried-out," **Bonnie Mulieri** wrote in March. Her daughter Gina, 11, has been suffering from brain tumors since she was 7.

A mother of six, Mulieri began blogging about her family's experience in January 2008, the first time Gina's tumors grew back after intensive chemotherapy. "I just laid it out and by the end of the page I had convinced myself there was hope still," she said.

Gina has relapsed two or three times since. "The blog keeps me centered," Mulieri, 41, said. "It allows me

to express my feelings about what's going on with her, my frustrations — the happiness, the sadness."

Her blog, "NoEvidenceOfStinkinTumors," is kept on CaringBridge.org, a nonprofit that hosts free sites for families with serious health issues.

"This blog keeps our feet on the ground . . . and keeps our spirits up," she said. "I hope my readers feel a little better at the end of the day after reading what I've been going through."

Meanwhile, Gina remains positive through her thinking. "I could climb to the tallest mountain and scream, just scream, but it won't change anything," Gina said. "You just got to believe. You can get through anything, just believe."



Kerry LaRosa of West Islip
Leukemia survivor (pictured with husband Anthony and son Michael)

Kerry LaRosa, a cancer survivor, wife and mother, juggles caring for her family and her passion for the Internet.

When she's not looking after her son Michael, 3, she spends much of her time on the Internet talking to other survivors, she said.

She was diagnosed with leukemia at 33, when her son was 17 months old. She spent a month undergoing chemotherapy in a hospital. While away from her son, LaRosa said she was terrified by one thought.

"My biggest fear was that he was so young he wouldn't even remember me if I died," she said.

To cope, she too turned to the Internet. For her, hope came in seeing her son's face on her computer screen. Through video chats, LaRosa said she saw her son often and even read him books.

Her time in the hospital, she said, was made bearable through the Internet. "If I didn't have my laptop, I don't know how I would have done it," LaRosa said.

When she returned home, she turned to social media to keep her family and friends aware of her condition. "Facebook was like a lifeline to me," LaRosa said her page was a way to talk to people when a phone conversation was just too tiring.

On various sites, LaRosa said she continuously updated her family and friends on her condition, found other young cancer patients, and joined support groups to share her story.

"It's amazing to talk to people who are in similar situations as you," she said. "It's great to share good news and cry together . . . If you have something you need to get out of your system, you can post it."

Cancer-free since May 2008, LaRosa continues to make lasting connections with people struggling with illnesses.

"I'm on the computer all the time," LaRosa said. "When I post that I have been in remission for two years . . . and when I see my girls from the cancer group . . . it means something. They can really understand."

'I think we can save lives'

ONLINE from A4

further.

In January of 2009, Sotomayor — who said the island lacked support for young adults faced with serious illnesses — founded the Long Island chapter of a Manhattan-based cancer support group called "I'm Too Young For This."

The nonprofit, which has more than 45 chapters nationally, brings together young cancer patients through social media networks and in-person meetings. The island's chapter has local "happy hours" around Long Island, as well as lively online discussions. On Thursday, "I'm Too Young For This" will host its fourth annual fundraiser, The Stupid Cancer Un-Gala at Taj Lounge in New York City.

Paul Mihailidis, an assistant professor at Hofstra University who studies the evolution of social media, said a number of people have formed virtual support groups. "People now have a place where they feel comfortable and free in global ways," he said.

A vital connection

Marsh, now 27 and cancer-free since September 2005, has continued her online activity and feels that connecting through the Internet for some can be a matter of life and death. She discusses cancer in young people on her blog, Facebook page, and most recently on Twitter. "I think we can save lives by blogging and using social media," Marsh said.

Mihailidis said many find comfort in the anonymity of the Internet as well as the ability to transcend physical borders through various sites. "The bottom line is when you can find new platforms for people coping with illnesses that gives as much hope as any medications," Mihailidis said.

Kevin Christman, 28, of Wantagh, who suffers from cerebral palsy, uses a wheelchair and has speech and motor problems, says the Internet allows him to do things his physical condition forbids. He said he has researched the rights of the disabled on websites, started an online petition against proposed budget cuts to programs



Resources

- The Planet Cancer: planetcancer.org
- CureTogether: curetogether.com
- PatientsLikeMe: patientslikeme.com
- Inspire: inspire.com
- Alliance Health Networks: alliancehealth.com
- HealthCentral: healthcentral.com
- I'm Too Young For This: i2y.com
- Cancer Survivors Network: csn.cancer.org
- Mayo Clinic: mayoclinic.com
- WebMD: webmd.com
- Cancer Care: cancercare.org
- University of Texas' MD Anderson Center: mdanderson.org
- imermanangels.org/blog
Matches and individually pairs a person touched by cancer with someone who has fought and survived the same cancer.
- livestrong.org
Olympian cyclist and cancer survivor Lance Armstrong's blog
- pagingdrgupta.blogs.cnn.com
Blog by CNN's Dr. Sanjay Gupta

he uses, and mostly recently, joined a Facebook group testing the Metropolitan Transportation Authority's \$1.2-billion cuts to its Able-Ride bus service in Nassau County.

"Online is where I'm most independent," he said. "I feel like I'm living the life I want to live instead of the one I have to work around," said Christman, a teacher's assistant at United Cerebral Palsy Association of Nassau County.

Not a medical substitute

While Christman and others say they would recommend using social media sites to the chronically ill, some caution that the Internet has its drawbacks.

According to the March study, about 2 percent of adults living with chronic disease report being harmed by following medical advice or health information found on the Internet. Dr. Elizabeth Carl, a clinical psychologist with practices in Huntington and Centerport who is the former president of the Media Division of American Psychological Association, has studied how media and social change effects psychology. She said she has spoken to several of

her patients about the benefits of finding online support groups. Carl said the Internet can "empower people to do things for themselves and their community."

However, she also warns, "You really have to verify the information because it can be inaccurate and also you have to be careful not to expose your identity."

David Pulli, director of patient and family services for the American Cancer Society Manhattan Office, also said patients should be careful. He said his organization and medical workers often encourage patients to do Internet searches about topics such as their illnesses, the effects of drugs, and support groups.

Hampton Bays resident Jacqueline Lederman, 23, who was diagnosed with leukemia three weeks before graduation last year, cautions that social media is not a substitute for personal contact. She said she's confronted some of her friends who were quick to post well wishes on her Facebook page when she was in the hospital.

"I told them that this is serious, this isn't something you can Facebook," she said. "I need a phone call."



Howard Cohen of Seaford
Suffers from cerebral palsy

Howard Cohen, 50, of Seaford, suffers from cerebral palsy, a disorder that requires him to use a wheelchair and affects his motor skills and ability to communicate. He speaks slowly and can sometimes be hard to understand.

Cohen, a teacher's assistant at United Cerebral Palsy Association of Nassau County, uses Facebook and AOL Instant Messenger to talk to friends and family. For him, the Internet is a way to escape his disability.

When he's online, he has no problem sharing stories and recalling the day's events. He easily types messages and changes his Facebook status regularly. The Internet and social media sites allow his disability to get out of the way, he said.

Through online discussions, Cohen said he communicates with people clearly and effectively.

"I feel I am equal when I talk to my nephew [online] and we can have a normal conversation."