

During Times of Illness, Updates Just Clicks Away

By Michael Alison Chandler
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Friday, August 18, 2006; B03

The first posting from Anne Rohall came a little after noon Dec. 11, 2004: *Our beautiful baby girls, Conley Marie Rohall and Nora Walsh Rohall, were born by C-section on December 7, 2004 at 24.6 weeks at Inova Fairfax Hospital.*

The posting included their height (about 11 inches each), weight (1.1 and 1.5 pounds) and a description of their first day in the world: *The team of doctors whisked them away very fast to the neonatal intensive care unit, so we weren't able to see them or hold them.*

Their premature delivery, which was caused by a rare and often fatal syndrome that affects identical twins, prompted an outpouring of support and concern from friends and family. Too much support, in fact, for the Falls Church couple, who were reeling with two babies in critical condition and unable to manage calls that came at all hours.

"There were no answers," Anne Rohall said, "and I didn't want to tell anyone my child might be dying."

So she and her husband, Jim, stopped talking and started typing. They began corresponding with friends, relatives and their extended circles through a Web log at <http://CarePages.com> after Jim Rohall saw a flier at the hospital.

The service, designed to help people dealing with medical situations communicate with the outside world, gave the Rohalls the emotional distance they needed in those first difficult days. Instead of suffering through one phone call after another, they were able to post photos and messages on a password-protected site -- on their own time and in their own way.

But in the tradition of the Web, what people intend often turns into something unexpected. Although the site allows people to put their loved ones at arm's length, it also opens access to a larger audience of neighbors, co-workers, distant relatives and complete strangers.

For the Rohalls, what began as a practical, detached way to pass along information turned into new ways of coping and also caring for the loved ones who logged more than 10,000 visits to the site.

"It helped me maintain control," Anne Rohall said. If she tried to talk to somebody about her babies' precarious status, she said, she would break down within two sentences. She couldn't afford to do that. "You couldn't allow yourself to grieve. . . . You had to be so on the ball so you could advocate and make decisions," she said.

The earliest dispatches were quick, urgent blasts written at home in rare moments away from the neonatal intensive care unit.

Dec. 13, 2004, at 9:30 a.m.: *Conley needs prayer today, we're waiting for a [CAT scan] to see if she has bleeding in the brain. They think she may be having seizures. Also, she may need surgery to close a valve in her heart that hasn't closed because she is such a preemie. It's causing blood to flow to her lungs, which the docs are able to draw out, but we are scared for her. Pray, pray, pray!*

Later, the entries became longer, with descriptions of medical procedures and specific requests for prayers, such as this one posted Jan. 8, 2005, at 10:46 a.m.:

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Nora's Prayer: Please pray that the steroids work SOON and that Nora's tummy continues to handle digesting milk.

Developed by a Chicago-based company, the service is free to users and has grown quickly over the past year, from about 12,500 sites to more than 50,000. It is now licensed, at a cost ranging from \$3,000 to \$500,000, to 500 health-care facilities in the country, and the company has plans to expand to long-term care facilities.

A similar service is offered by CaringBridge, a nonprofit that has hosted about 44,000 patient Web sites, and at least one hospital has designed its own version of the blog.

The medically geared message boards have been useful for people with long-term illnesses whose status changes incrementally or for people who are struggling with serious afflictions and want some refuge.

"It allows the creator to set the limits" of what he or she wants to share, said Holly Senn, a child-life specialist at Inova Fairfax Hospital for Children, who recommends the service to families of children who have blood diseases or cancer. She said the ability to control information is key, because it can protect patients or family members from becoming emotionally exhausted by prying questions.

Anne Rohall said the writing started out like a job. She would go to the hospital each day, record her babies' ventilator settings and their medications and then condense what she learned for her readers each night at home. "It could have been someone else writing those dispatches," she said.

As the Web site recorded the ups and downs of micro-preemie life in medical terms, messages poured in. First, it was friends and family members who responded, but within weeks, the Rohalls were receiving notes from extended relatives, friends of friends, friends of co-workers, childhood classmates they hadn't seen in 20 years, people they never knew. Prayer chains spread across the country, and notes came from Texas, Nebraska, California and Tennessee.

A neighbor offered to help baby-sit for their nearly 2-year-old daughter, Ella. Other mothers of premies and people familiar with the babies' condition, twin-to-twin transfusion syndrome, sent advice and words of encouragement. The principal at the Washington high school that Anne Rohall attended wrote to say that she shared each posting with students and teachers and that they prayed together.

Mary Olson, a friend of Anne's great-aunt, logged on every morning from her home in Elkhart, Ind., as did her husband and two grown daughters. When a day passed without an update, Olson said she would get nervous and call her friend.

"You feel like you are involved," said Olson, who had not seen Anne since she was a baby. "It puts you there in that waiting room, waiting to hear with that family."

She also felt she was playing an important role in helping Anne: "She needed a strong support system, and she got it, whether it was from Indiana or Boston, Massachusetts," she said.

One night, after Conley had been struggling from prolonged renal failure and increasing lung failure, Anne Rohall called on everyone to help.

Jan. 4, 2005, 10:40 a.m.: Conley is critically sick and deteriorating. Please pray especially hard for her today. . . . I have told Conley that she doesn't have to be here any more if she is too tired and too sick. I have told her (and Nora, too) about the over 100 messages of love and support and hope and prayer from all of you on this Web site. I have told her that we all will love her and be proud of her just as much (and more) if she is an angel in heaven and that we all have been privileged to have known her. Please pray that if a miracle is appropriate then God gives us one.

The growing group of well-wishers sent back tearful messages and virtual hugs. When the next day's posting said the baby was slowly improving, their responses sounded like a collective sigh of relief.

Miracle babies. Hosanna in Excelsis. Wow wow wow wow. Thrilled, Happy, Elated . . . !! Rah, Rah. Praise God, so thankful!.

Anne said she occasionally worried that her twins were becoming "some kind of Discovery Health Channel show." But ultimately, she was beginning to rely on the positive feedback, prayers and encouraging notes.

"It became its own little machine of give and take, and we just felt like we weren't alone," she said.

As the family cleared more medical hurdles and there were more encouraging signs, Rohall said she felt safer sharing more details.

Jan. 24, 2005, 10:26 a.m.: *Yesterday afternoon, at 02:30 p.m., Miss Nora Walsh took her first breaths without the assistance of a mechanical ventilator! Praise the Lord! She also sneezed and made a little noise -- her first noise since that tiny cry she made when she came out of me. Nora is now able to cry.*

In the next months, she recorded the first day the babies wore clothes, the first time they ate without a feeding tube, the day Conley's medical record status changed from "critically ill infant on vent with significant risk for deterioration" to "fragile infant," and those long-awaited days when Nora and, later, Conley were able to go home.

More than a year later, at their Falls Church house, two chubby-cheeked twin girls -- whose health problems are in the past -- finished their nighttime bottles and then clambered from their parents' laps. As Conley scooted across the hardwood floor toward her twin, Anne Rohall looked in astonishment at the child who once could have fit in the palm of her hand. "She doesn't know she's a miracle yet," she said.

With the babies' first days recorded online, she said she plans to share the Web site with them when they get older. She and her husband occasionally update it.

As for her, when she looks back on all the emergency dispatches that she typed with numb fingers, she realizes she has undergone her own transformation. Now, with the crisis behind her, when she scrolls through the blog, she sits at her keyboard and cries.

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