

Fight against malaria: Battle of life and death

2:00 am, November 26, 2009

Part 1

Easter morning, 2008.

Dawn Dubsy opened her eyes, her consciousness rising through a soup of painkillers and sedatives. She had been waking sporadically, and every time she did, those watching over her hospital bed shared the same bleak thought:

This could be the day she figured out what happened.

It had been one month since Dubsy, then 32, a pediatric nurse fresh from a trip to Africa, entered a Chicago emergency room with a crushing headache and a 103-degree fever -- signs, she correctly guessed, that she had contracted malaria, a disease that claims nearly 1 million lives each year in the developing world.

That human wreckage goes largely unnoticed here. An army of public health workers eliminated the mosquito-borne illness in the United States more than 50 years ago, and on the rare occasion a traveler brings it home today, it is usually no match for Western medicine.

Dubsy's case was different. Despite the efforts of 15 doctors, the microscopic parasite that causes malaria rampaged through her bloodstream, blowing up cells, clogging veins and arteries and shutting down vital organs. Her skin blistered and turned purple. She started to die an inch at a time.

A barrage of drugs finally subdued the parasite, and Dubsy pulled through. But survival had come at a price -- one she was just starting to recognize.

Dubsy peered at the bandages covering her body. Her face clouded with confusion. She looked again. At last, she spoke.

"Mom," she said, "where are my arms?"

"Oh, Dawn," her mother replied. "Your arms and legs are gone."

Malaria had destroyed so much of Dubsy's tissue that a surgeon had to amputate her limbs just below the elbows and knees. The procedure saved her life but left her utterly transformed.

Dubsy had been a woman of fierce independence, an adventurer who ran marathons, skied the Rockies and traveled the world on little more than a whim. Now she was helpless, unable to even sit up by herself.

It was too much to fathom -- too much to bear. And so, in a furious voice, Dubsy asked a question:

"Why didn't you let me die?"

Her mother begged her to never say that again, but the thought endured, following Dubsy along a path of pain. Only gradually would a new purpose reveal itself, one that joined her suffering to a titanic global struggle.

Why wasn't she dead?

The answer was simple. Her life's work had yet to begin.

Nothing to fear

No one was surprised when Dawn Dubsy decided to become a nurse after graduating from Andrew High School in Tinley Park. She was a born caregiver, covering up for her older siblings' teenage indiscretions and comforting her mother through the strain of divorce.

Yet her interest in the profession was only partly benevolent. What really appealed to her was its promise of freedom.

So after earning her degree from the University of Iowa in 1998, she was gone, finding work in California, Mexico, Colorado and Hawaii and

spending her off time in exotic pursuits. She dove with sea lions in the Sea of Cortez, surfed the big waves of the Pacific and shot down black diamond slopes strapped to a snowboard.

"She didn't think about things -- she just did them," said her best friend, Olivia Bradley. "Later on she might say, 'I was really scared,' but I could never tell."

Dubsky eventually drifted back to Chicago, eager to spend more time with her nieces and advance her career. She had discovered an enthusiasm for children during stints as a summer camp nurse, and in 2004 she took a job in the organ transplant unit of Children's Memorial Hospital.

But as Dubsky reached her 30s, she felt the old itch for change. She had long had an interest in fashion, and with an eye toward a possible career switch, she took classes at the International Academy of Design and Technology in the Loop.

It was there one day in late 2007 that she saw a flier advertising a two-week retreat to study textiles and jewelry in the west African nation of Ghana. The pairing of two passions, design and travel, was irresistible. She quickly signed up.

Most of her family and friends thought nothing of it. Only her mother, Deborah Chandler, was nervous.

She was a junior high school teacher and had taught African history as part of a social studies class. Despite Ghana's reputation as a relatively safe and stable country, her daughter's trip stirred a host of frightening thoughts. What about political strife? What about sanitation? What about disease?

Dubsky told her mother everything would be fine. And on Feb. 4, 2008, she left O'Hare International Airport as planned, with one suitcase lightly packed with clothes, the other crammed with medical supplies she had volunteered to ferry to a Ghanaian health clinic.

"Not to worry," Dubsky wrote in an e-mail to her mother the next day. "I'm safe. I'm here. It's beautiful."

So it was -- hot and crowded yet vibrant. There was so much to see and do, but for Dubsy, the first order of business every morning was to mist herself with bug spray. It was an imperfect defense against the threat of disease-carrying mosquitoes, but she figured it would be enough.

Dubsy had declined to take medication designed to shield her from malaria. Though she knew the disease could be a killer, she wasn't particularly concerned: A Ghanaian acquaintance had said mosquitoes would be rare that time of year, and Dubsy judged the medication's possible side effects, from intestinal distress to hallucinations, to be the greater hazard.

Besides, she was laid-back by nature. She wasn't even alarmed when, lounging by a resort swimming pool, she felt a slight irritation on the back of her right leg and realized she had been bitten.

She was an American, young, healthy and strong. She had access to the world's most advanced medical care.

There was nothing to fear.

Under her skin

The invasion begins the moment an infected mosquito starts to feed. The insect's saliva carries a few dozen or so malaria parasites, which resemble microscopic earthworms, into the body of their new host. Within an hour, the circulatory system propels them to the liver.

There, they penetrate the cells of the organ and multiply. It is painless. For about a week, the host doesn't feel a thing.

Then the swollen liver cells rupture, dumping swarms of hungry parasites into the bloodstream. They enter red blood cells, growing fat on oxygen-carrying hemoglobin before replicating again.

The cells bulge and explode, sending forth new waves of attackers, and the cycle repeats. By the time the host notices that he is unusually fatigued, the incursion has become a takeover. Hundreds of millions of

malaria parasites can be swimming in his veins and arteries.

Sometimes malaria even turns the host's body into the enemy. The immune system counterattacks with such ferocity that it becomes an even greater destructive force than the parasite.

Experts say someone with a severe case in the developing world probably would die before the disease displayed the full range of its power. That's the thing about Americans who contract malaria. Technology can keep them alive long enough to find out just how bad it can get.

Too sick to be afraid

Dubsky felt drained as the retreat neared its end. When her plane took off for home, she dozed for nearly the entire 22-hour journey.

The weariness lingered after her return on a Tuesday, but she wrote it off as jet lag. It wasn't until that Friday, 13 days after she had been bitten, that she knew something was wrong.

She dragged herself to her shift at Children's Memorial but grew steadily weaker throughout the day. Her stomach soured. Her head felt as though it was being squeezed into pulp.

She left early and got a few hours of sleep at home. When she woke, drenched in sweat, she took her temperature. It was 103 degrees.

Early the next morning, she took a cab from her Lakeview apartment to Northwestern Memorial Hospital and told the emergency room doctor what she thought was happening. A blood test confirmed it, and Dubsky left the diagnosis on a friend's voice mail:

"I got da malaria!" she said in an exaggerated Chicago bray.

Though her family and friends raced to the hospital, Dubsky wasn't terribly worried. The infectious disease specialist who examined her on Saturday afternoon judged the case to be "uncomplicated," with no sign of shock or other serious symptoms. Only 2 percent of Dubsky's blood cells were infected (it can go up to 50 percent).

The doctor prescribed a standard treatment: a week's worth of quinine sulfate tablets. But quinine isn't easy on the stomach, and Dubsy repeatedly threw it up. She insisted on getting her medication through an IV, but hospital staffers said taking it by mouth would work faster.

After a wretched night of shivers and chills, Dubsy grew far worse. Her fingers and toes tingled. Her blood pressure plunged. Jaundice turned her skin as yellow as old newsprint.

Worse, a test suggested the onset of DIC, or disseminated intravascular coagulation, in which the body's blood-clotting system spins out of control. It is a major complication: Doctors sometimes joke grimly that DIC stands for "Death Is Coming."

Late that afternoon, Dubsy's hands felt like clubs, her lower legs as though they were encased in ski boots. She hobbled to the bathroom but was unable to urinate, a sign that her kidneys were starting to fail.

On her way back to bed, Dubsy peeked in the bathroom mirror.

"Mom, look at me," she called out.

Her mother glanced up. Dubsy's lips had turned blue.

A few moments later, Dubsy's breathing grew labored as tiny blood vessels, dilated by her body's wild response to the infection, leaked fluid into her lungs. It was a harbinger of septic shock, a potentially fatal condition.

Hospital staffers raced Dubsy to the intensive care unit, where she signed papers directing the physicians to do all they could to save her life.

Her brother, Tom, a pipe fitter and former junior hockey player, wept as he begged Dubsy to fight. Her mother, kneeling at the foot of Dubsy's bed, sobbed that she was terrified.

"Mom," Dubsy replied, "I'm too sick to be afraid."

It was the last thing she would say for weeks.

Losing her grip

A few hours later, Dr. Richard Wunderink, director of Northwestern Memorial's intensive care unit, met his sedated patient. He had cared for a few people stricken by malaria over the years, but none had been so sick.

A ventilator was doing the breathing for her. She was about to be hooked to a dialysis machine that would stand in for her failed kidneys. And even though she was on three medications to increase her blood pressure, it was still perilously low.

Then there was her skin. A patchwork of purple blotches was breaking out on her belly, nose and especially her lower legs and arms. Her darkened fingers had curled into cold, stiff claws.

Some of that was due to the medication combating her low blood pressure. The drugs caused the vessels leading out of her torso to constrict, keeping the blood concentrated near her vital organs and brain. But that meant little was reaching her extremities.

It was a regrettable but unavoidable consequence of the treatment for septic shock, Wunderink said later. If Dubsy's heart, lungs, liver, kidneys and brain didn't receive sufficient blood flow, she was going to die.

After a few tense days, her vital signs improved. Her skin did not.

The coldness crept upward from her hands and feet, even after she'd been taken off blood pressure medicine. Large blisters boiled up and burst on her arms and legs, evidence that malaria-deformed cells had blocked the blood flow to her skin.

Wunderink, concerned that her brain had suffered similar blockages, ordered a CT scan. To his surprise, the image was flawless. Regardless of how thoroughly malaria had ravaged Dubsy's body, her brain was intact.

With that, the doctor knew it was time to send Dubsy along. The parasite

had been suppressed to a nearly undetectable level, and Dubsky was stable enough to be transferred to a burn unit, where a specialist could treat her devastated skin.

Wunderink was confident Dubsky would live, but he was equally sure that she was going to lose part of her body. He had known it the moment he saw her. The only question was where it would end.

Her living nightmare

The ambulance pulled away from Northwestern Memorial and headed south, bound for the University of Chicago Medical Center. A convoy of Dubsky's family and friends followed.

Despite Wunderink's optimism, Dubsky was still in critical condition. Forty percent of her skin was blistered. Her limbs were dotted with ink marks where the doctors had tried to find a pulse.

Yet inside the ambulance, Dubsky slumbered. Time had stopped, but her dreams went on.

She was underwater, a scuba diver, and though she was running out of air, she couldn't break the surface. She felt a surge of danger, as if she were fleeing something menacing but couldn't get away.

Then she was trapped in a casket. Two men with a chain saw argued over whether to cut the box in half. She wanted to scream, but no one could hear her, no one could help her, as the saw roared to life.

Part 2

Malaria: Four limbs lost, and then a road to recovery

Dawn Dubsky struggles with life as an amputee, but finds new purpose

November 27, 2009 | By John Keilman | Tribune reporter

THE LAST OF TWO PARTS: Dawn Dubsky contracted malaria during a trip to Africa, and the infection became a personal catastrophe. She has been transferred to the University of Chicago Medical Center for surgery, which will change her life irrevocably. (See Part 1.)

Dr. Lawrence Gottlieb lived in a world of stress. He was a burn unit surgeon who treated ghastly, complicated wounds -- skin and muscle charred in house fires or ravaged by flesh-eating bacteria. But the case before him on Feb. 29, 2008, was pushing the pressure to a level even he rarely felt.

Dawn Dubsky was a young, athletic nurse who'd been stricken by malaria. The mosquito-borne illness had unleashed a storm in her body, triggering organ failure, a blood pressure crash, and clotting in the veins and arteries of her extremities.

She had stabilized, the parasite all but vanquished from her bloodstream, but irreversible damage had been done. After examining the tissue beneath Dubsky's ravaged skin, Gottlieb carried a terrible message to her family.

"This is the situation," he said. "I think we can save your daughter's life. But I'm not sure you're going to want me to, because you have to recognize what this is going to mean."

The muscle in Dubsky's lower arms and legs was dead, he said. He had no choice but to amputate all four of her limbs.

Her parents were stunned. They had expected some tissue loss, maybe a few fingers or part of a foot. Never had they imagined anything this severe.

Gottlieb left them to talk it over, not expecting an easy decision. Indeed, some of Dubsky's relatives were struggling over whether to pray for her life or death.

But when the surgeon returned, Dubsky's parents didn't hesitate. They knew their daughter, they said. She was a fighter. She would overcome this, no matter what happened.

Three days later, Gottlieb removed Dubsky's legs just below the knees, and her arms just below the elbows. A dozen more surgeries, aimed at preserving the joints and sealing the wounds, would follow.

When Dubsky's family was allowed to see her, the sight was so unreal they could barely process it. This would be her body from now on. What would it do to her life? How would she cope?

How would they tell her?

In and out of sleepIn the days after the amputation, Dubsky occasionally

opened her eyes and glanced around before slipping back into sleep. Slowly, her awareness grew. So did her family's anxiety.

The hospital's counselors had told them not to lie, but it was difficult advice to follow when Dubsy asked for a special ring or stared at what remained of her legs.

"My fingers are freezing," she told her father one day. "Hold my hand."

After a moment's hesitation, Tom Dubsy responded: "Dawn, you don't have a hand. I'll hold your arm."

He wrapped his fingers around her biceps, and she drifted back into oblivion. As far as he could tell, she had not understood what he said.

But Easter morning, three weeks after the amputations, Dubsy woke and asked her mother, Deborah Chandler, what had happened. When Chandler told her, Dubsy fell into a rage, demanding to know why she hadn't been allowed to die.

From then on, Dubsy's conscious hours were an emotional whirlpool. She was numb to everything one moment, painfully aware the next.

She wondered aloud whether her boyfriend, Scott Noorthoek, a constant presence at her bedside, would leave her. She worried that she'd never be able to have children, despite the doctors' insistence that her reproductive system was unharmed. She slept poorly, browbeat the nurses and thrashed violently in her bed.

"Sometimes I'd be happy when I was headed back to the operating room (for follow-up surgeries)," Dubsy said later. "I knew for that one day I wouldn't feel anything."

Her family wasn't so lucky. Dubsy's father was tortured by the ache of powerlessness until a nurse handed him a photocopied newspaper story about Erica Van Zuidam, a college student from the far south suburb of Beecher.

In 2005, Van Zuidam suffered an attack of bacterial meningitis that led to sepsis and the loss of her hands and feet. Fifteen months later, she was back in school, walking on prosthetic legs, doing homework with the metal pincers that had replaced her hands.

Revitalized, Tom Dubsy announced to the rest of the family: "If you want to cry, go cry outside. There's no more crying inside this room. We've all got to think positive from now on."

Struggling to walk againIn May 2008, after 2 1/2 months at the University

of Chicago, Dubsy was transferred to the Rehabilitation Institute of Chicago, not far from the Magnificent Mile. She was glad to be out of the hospital, but little came easily at her new home.

Her prosthetic arms were bulky and hard to control. And though her attempt at walking started well, the skin covering the stumps below her knees soon blistered as her weight pressed down on her artificial legs. She had to stop after only a week.

Every day was a struggle. Every night was a poisonous brew of nausea and insomnia.

Her despair bottomed out when she returned to Northwestern Memorial Hospital for treatment of a calcium imbalance. As the nurses poked her arm and neck, searching for a blood vessel to accept an IV line, she grew so miserable that she hoped something would go fatally wrong with the procedure.

But Noorthoek, her boyfriend, talked her down. Her feelings were normal, he said. Things would get better.

She finally relaxed. The nurses found a vein, and the medication began to flow.

It turned out that Noorthoek was right. Things did get better. Dubsy's nausea and insomnia cleared up. She got lighter prosthetic arms that were easier to use. And she found her old spirit coming back.

Maybe it was the memories of the desperately ill children she had treated as a nurse. No matter how sick they were, no matter how certain their deaths, they never gave up. They always clung to life.

Or maybe it was the sum of the small pleasures she still enjoyed: the laughter of her nieces and nephews, an unexpected visitor, a favorite song playing on the radio.

She was starting to sense that joy was still possible. Life would be different, it would certainly be hard, but maybe it could still be good.

After two months at RIC, Dubsy decided to leave. The skin on her legs remained too fragile for walking, but she was tired of sterile medical corridors. She decided to join Noorthoek in a ground-floor apartment in Roscoe Village.

He took her to see it a few weeks before the move, setting her down on a couch in the living room. The TV was on the opposite wall, perhaps six feet away. But for Dubsy, it might as well have been six miles.

For all she had learned, there was still so much she couldn't do. She couldn't

cook for herself. She couldn't leave the apartment unless someone opened the door for her. She couldn't even get across the room to that television.

She had wanted the real world. Here it was.

As Noorthoek poked around the kitchen, Dubsky sat marooned on the couch and began to cry.

Loving support They were an unusual couple from the beginning.

Noorthoek was at the Wicker Park Tavern one summer night in 2007 when Dubsky flirtatiously challenged him to a dance contest.

"She thought she was good, but I beat her," Noorthoek recalled. "And I let her know that I beat her."

It was a fitting start to a relationship that seemed more like two buddies hanging out than a storybook love affair. They were an easygoing couple, their affection couched in sarcasm and trash talking. Noorthoek, then 30, nicknamed his new girlfriend "Nightmare."

They had been dating only half a year when Dubsky contracted malaria. Yet Noorthoek gave up a new job in finance to stay with her. He cared about her and thought it unforgivably cruel to walk away at a perilous time.

When he volunteered to move in with her, Dubsky's family questioned whether he could handle the commitment. But day after day he lifted her out of bed, helped her to the bathroom and changed the dressings on her surgical wounds.

Sometimes he felt like a parent taking care of a child. Inevitably, perhaps, resentment began to stir.

Noorthoek had put aside his career and social life for Dubsky, and she wasn't always bursting with gratitude. If he came home late or seemed too casual about his responsibilities, she was quick to chew him out.

Dubsky, meanwhile, felt isolated in an apartment she couldn't leave without help. She treasured her independence, and it was mortifying for her to have to rely so heavily on someone else -- particularly when that person was her boyfriend.

"It's terrible to be on the other side (of caretaking)," she said one day. "It's embarrassing. You don't ever want it. Hopefully it will get better."

Bound by experience The basement of the University of Illinois Medical Center was a warren of hallways, offices and curtained-off patient bays, an expanse of institutional blandness that gave little hint of the dramas playing

out in its corridors.

Here was a man trying out a new prosthetic leg, walking so smoothly it was impossible to tell which limb was artificial. Here was the victim of an industrial accident, testing a pair of running blades by kicking across the floor like a cancan dancer.

And here was Dubsy, watching enviously from her wheelchair, waiting for her turn.

It was mid-July, one year since she had last tried to walk. Her skin had been reinforced with new grafts. She had a new pair of artificial legs. She was ready to try again.

Dubsy leaned forward in her wheelchair, and, with the help of prosthetist David Rotter, pushed herself into a teetering stance.

"What do you feel?" Rotter asked.

"I'm good," Dubsy said. "I just wish I had something for balance."

"You do," Rotter said. "You have me."

Her plastic and metal feet, shod in a pair of New Balance sneakers, shuffled forward a few inches at a time. Her face clenched with effort. Walking on prosthetic legs, Rotter said, can require far more energy than walking on natural limbs.

"Congratulations, Dawn," he said. "It's your first steps."

Dubsy collapsed into her wheelchair. Before malaria she had been a runner, an outdoorswoman and a world traveler. It was a gift just to feel physical exertion again, to feel the sweat trickling down her brow.

It was also gratifying to find a place in the small but close community of amputees. She formed a friendship with Erica Van Zuidam, the woman whose story had encouraged Dubsy's father. Dubsy was reassured to learn that the bubbly Van Zuidam still faced her own hurdles.

But Van Zuidam stressed that it was folly to dwell on what had been lost when so much still remained. Dubsy took the lesson to heart, and soon she found her own chance to be an inspiration.

In September, Kristi Turner, Dubsy's occupational therapist at RIC, asked her to come by and speak with a woman just starting to recover from a quadruple amputation. It would be good for both of them, Turner said.

Loretta Foote, 48, of Rockford, had lost her limbs to an infection that caused

uncontrollable blood clots. When Dubsy wheeled herself on to the ward, Foote was sprawled on a blue exercise mat, trying to build her strength by swinging weights strapped to her shortened arms and legs.

Within minutes, Foote and Dubsy were chatting like old friends, bound by experiences few others could comprehend. They shared stories about phantom limb sensation, the feeling that they were still whole. They commiserated over how miserable they felt in the heat ("It's because you've lost so many sweat glands," Turner said).

And they talked about pain. All the medication that accompanied their surgeries could never fully mask the hurt.

"Eventually most of the pain goes away?" Foote asked hopefully.

"Yes," Dubsy said. "It goes away. It just takes a little time."

Finding new purpose For all the difficulties of Dubsy's physical rehabilitation, she could still manage some things with little trouble.

The hook on her prosthetic right arm was slender enough to rap a keyboard, and she spent hours surfing the Internet on a laptop computer. The chief subject of her investigation was malaria.

She wanted to know how it worked, why it attacked her with such ferocity, and whether different medical care might have made a difference. But as she pored over research papers and case studies, another set of facts grabbed her attention.

Among all the maladies gripping the developing world, few are more devastating than malaria. The latest accounting by the World Health Organization estimated that in 2006, the disease produced nearly 250 million infections and 881,000 deaths.

Ninety percent of those who died were in Africa -- and 85 percent were under 5 years old.

The more Dubsy learned, the more unfair it seemed, and the more she felt obligated to help. But she wasn't sure what she could do until serendipity gave her a nudge.

New York-based philanthropic consultant Christina Barrineau was starting a new anti-malaria campaign when she stumbled across a brief account of Dubsy's plight online. Intrigued, Barrineau arranged a meeting, believing Dubsy could bring new attention to the disease.

At a Roscoe Village Starbucks, Dubsy said she wasn't interested in becoming

anyone's spokeswoman; she wanted to do something that would take advantage of her medical training. Barrineau suggested that she start her own group.

So with the help of her cousin, Carrie Beltz, Dubsky drafted plans for America Against Malaria, a nonprofit group that would teach Ghanaians about the disease and train the country's health professionals to defeat it.

As the plan took shape, Dubsky's family saw a familiar personality return. Her ambition and love for children had found a new vessel.

"That's who Dawn is," said her mother. "It gives her happiness. It gives her purpose and meaning. I pray that someday she sees some kind of good out of it."

Speaking simply Atop a stage in a Naperville church hall, Dubsky, now 34, took a nervous look at the crowd below. She wore a festive red blouse and a new pair of flared jeans that slipped easily over her artificial legs. Fortified by a few sips of wine, she was about to commit her first act of advocacy.

Clarke, a Roselle-based mosquito control company, was throwing a fundraiser on a chilly, rain-soaked October night to help pay for 38,000 bed nets for the Nigerian region of Kanke -- enough to cover every household. When the organizers learned about Dubsky from one of her relatives, they invited her to say a few words.

It was no simple request. What could she say about all she had been through?

She was a changed woman. Though her vitality and humor had returned, her family sensed a new seriousness within her, a new sense of mission. Her relationship with Noorthoek remained uncertain, yet for all its challenges, it had produced a depth of friendship and devotion she'd never experienced.

She had come so far, borne so much. She could have talked for days.

But she kept it simple. As a Clarke executive held a microphone to her mouth, she stressed in a quivering voice that she had contracted malaria after neglecting to take preventive medication. She didn't want to scare anyone away from the continent she was trying to help.

"Luckily, my life was saved, but millions of children in Africa, their lives aren't saved because they can't get to proper medical facilities to get proper treatment," she said. "So by donating tonight, you're probably going to save a child's life in Africa."

The crowd applauded heartily. Dubsky smiled.

And then, slowly, gingerly, she walked back to her chair.

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