

To the brink and back

One year ago, a simple shiver marked the start of a terrifying ordeal for Andy Marso. His losses are great, but at last, hope is growing again.



Occupational therapist Stephanie Wilkin works compression garments over Andy Marso's left arm as Andy's father, Harry, watches from the corner. In a therapy session, below, Andy struggles to write a few short sentences, including "Had trouble with the electric toothbrush."

Story by **LEE HILL KAVANAUGH** ■ Photos by **TAMMY LUNGBLAD**

The Kansas City Star

He wakes up in a hospital to all the bleeps and whirs and quiet hummings of machines that monitor a patient in intensive care.

I'm alive.

Bags of fluid loom over him. Tubes run into his arms. Images blur. A nurse is feeding him something delicious ...

Ice chips.

For more than a week, he's been sedated, on a ventilator, unable to swallow. Now he's breathing on his own.

When the nurse asks how he feels, he winks. He takes in the scene around his bed. His parents, his grandma, his youngest brother ...

All the way from Minnesota?

They stare at him with tired eyes, their hair disheveled. They tell him how lucky he is. He, Andy Marso, has survived a rare disease so monstrous that in hours it can wrench a healthy human being to the brink of death.

I'm alive.

But then he tries to move, and sees them. The things.

Swollen and purple, the things — his fingers — curl on their own against the win-

ter-white sheets. He feels them, but ...

Why won't they move?

He tries feeling the rest of his body, taking inventory. His feet?

I can't feel them! Are they there?

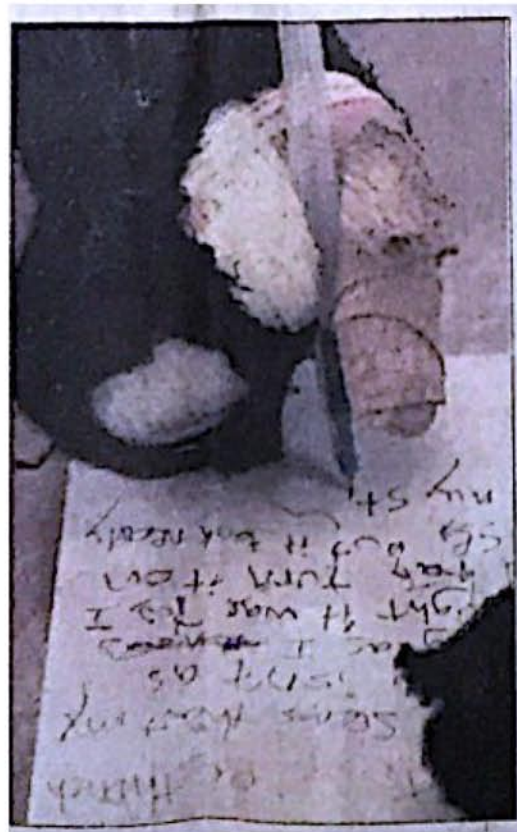
They are. Covered with blisters the size of golf balls, some weeping a watery ooze.

At least the worst is over, he thinks.

He's wrong.

Thousands of struggles lay ahead, along with loss, grief, endless tears. But with it all comes an enormous gift: unconditional love.

See **ANDY, A-6**



ANDY: Bacterial infection hits KU student hard, fast

Continued from A-1

April 27, 2004: Spring sunshine, dirt on the softball diamond as fine as powder, the beautiful *bink* of a bat on a ball.

Andy sits on the bleachers, taking notes on the first game of a double-header. A journalism major at the University of Kansas, Andy reports part-time for the *Basehor Sentinel* as a sports writer.

At this moment, deep inside the microscopic landscape of his cells, a horror looms.

A colony of microscopic bugs is growing inside his throat. Called *Neisseria meningitidis*, the life form looks like two kidney beans joined on one side. Like other bacteria, they feed on sugars from saliva. They're so small that thousands can fit on a period. No one knows how or when Andy was exposed. From 10 percent to 25 percent of people have the bacteria and never get sick.

Now the colony is on the move, searching for a portal into his bloodstream.

During the ninth inning of the first game, they slip in, foreign invaders in a sea of human cells.

Andy begins to shiver.

I must have the flu bug, he thinks.

But he doesn't have a bug.

Andy has millions.

Once the *N. meningitidis* bacteria enter the highways of the circulatory system, Andy is infected. He has the worst form of meningococcal disease: meningococcemia.

In less than a minute — the time it takes blood to carry oxygen from the lungs to the body's farthest outposts and back — the bacteria ride along, eating, reproducing and oozing trails of poison.

In minutes, so many bugs teem in Andy's blood that without medical intervention, he will die. Even among those who receive medical attention, the fatality rate for meningococcemia is 40 percent.

Andy's life clock is ticking.

He shivers more with each spring gust. *Why am I so cold?*

Andy doesn't have time to get sick. Not now.

In addition to holding a part-time job, he works as a student reporter for *The University Daily Kansan*. Stress-filled deadlines. Late nights writing. Studying for finals.

In just three weeks, he'll graduate, move out of Pearson Scholarship Hall and into a Kansas City apartment with two friends, and start a full-time job at the *Basehor Sentinel*.

But now, two innings into the second game, Andy's body aches. He trudges to his van. He can't stop shivering.

The 45-minute drive from Basehor to Lawrence is a slog.

His white blood cells battle the bacteria, but the trails of poison, acting as decoys, distract them.

The blobs of poison damage whatever they touch. When the poison reaches Andy's heart, the muscle pumps faster and not as efficiently. Already, tiny blood vessels are choking, beginning to die. Their supply of oxygen dwindles.

In a chain reaction, each problem in his body leads to another. The bacteria have the power to maim, to damage brains, to obliterate hearing and more.

When the much larger white blood cells encounter the globs of poison, they release a substance that makes blood vessel walls gooey. As more white blood cells swarm to the bacteria, they clump together on the sticky walls.

Blood keeps pulsing against the clumps. A blockage forms. Like a dam giving way, the vessel walls rip apart in a cellular tsunami.

The bacteria divide again and again.

Andy feels lousy. He calls his mother, Ginny, in St. Cloud, Minn.

She tells him to rest, see how he feels in the morning.

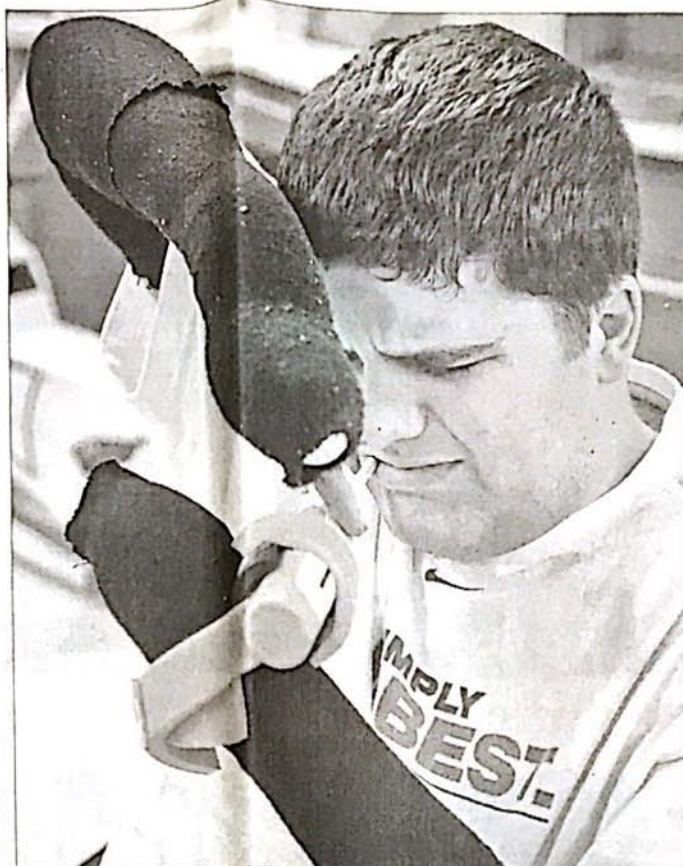
At the dorm, he drags himself up the stairs and collapses into bed. Light hurts his eyes. He wants to throw up.

He's too sick to write. His temperature is rising: 103 ... 104.

His body is struggling to heal itself. Platelets rush to plug the holes in the vessel walls, but they fail, their clotting ability destroyed by the poisons.

Now, the platelets add to the problems, hemorrhaging through the vessel walls. The leaks begin from Andy's tiniest capillaries. Blood seeps into pockets beneath his skin. Organs begin to bleed.

In the darkness he can't see the tiny rash popping out over his body. The spots look like pinpricks now, but by morning they will be nickel-size.



Andy struggles to use his thumb to turn on a battery-powered toothbrush strapped to his left arm. Photos by JAMMY LUNGBLAD/The Kansas City Star

Clay Britton, a senior from Olathe, lives four doors down from Andy in Pearson. They met their first night in college four years earlier, learning they shared the same dry sense of humor, the same obsession with KU sports, the same drive to succeed.

That April night, Clay learns that Andy is sick when Andy's roommate asks to crash on Clay's couch. Late the next morning, April 28, Clay knocks on Andy's door and hears a moan.

Andy lies curled in his bed, buried in blankets. He moans again.

Clay asks if he's been to the doctor. Does he need a ride?

Andy mumbles that he can't get up, and he lifts his arm to show Clay the spots.

Spots? People don't get spots when they have the flu. These look ugly. Angry. Clay and a friend hoist Andy down the stairs to Clay's car.

The three-minute drive to Watkins Memorial Health Center seems much longer.

The first nurse takes one look at Andy and whisks him into a back room. A medical team surrounds him, already inserting tubes.

The nurse returns to the desk. She tells Clay to wait in another room. But first, she says, wash your hands.

In the bathroom, Clay slathers antibiotic soap between his fingers. He thinks about how close he was to Andy's head as he carried him, and he begins to shake.

The Watkins staff suspect meningococcal disease when they see the telltale splotches. In 1994, a 21-year-old football player came into Watkins with the splotches. Three hours later, he died.

Andy doesn't know yet how sick he is. He's surprised when he learns he'll be taken by helicopter from Lawrence to the University of Kansas Hospital in Kansas City, Kan.

At the hospital, critical-care physician Steven Simpson is already preparing a drug for Andy called Xigris. It dissolves clots and reduces inflammation, and it might save Andy's life.

The whapping of the helicopter blades is loud. Andy looks around the cabin. He watches a woman read numbers from machines monitoring his vital signs.

Andy wants her to look at him, to nod at him, or smile. *Tell me I'll be all right.*

But she doesn't. She won't meet his gaze.

At 12:40 p.m., a doctor at Watkins calls the home of Ginny and Harry Marso in St. Cloud, Minn.

Only Harry is home, fixing himself a sandwich during a break from his job as a manager at the Fingerhut catalog company. Harry, who is well-liked by his colleagues, is a tall, modest man with thinning gray hair. He attended law school but decided he didn't want to be a lawyer.

Harry remembers only bits of the conversation: *Andy is sick ... possible diagnosis of meningitis ... transferred by helicopter ...*

He tries to call Ginny, leaves her a message. After he hangs up, he pulls "M" from an old set of encyclopedias. He reads about possible brain damage, amputations and death.

Ginny Marso, a divorce attorney, is having lunch with three other lawyers. A short, round woman with gray hair, she's nicknamed "the bulldog" for her grit in winning cases, especially if they involve children. Her law clinic handles mostly divorces and adoptions. Frequently she takes no fee. Jesus is her accountant, she says, and it'll all add up in the end.

She gets the message from her paralegal to call home. Andy is sick.

Ginny already knew that; he'd called the night before. But when she learns Andy is being airlifted to another hospital, her heart freezes.

In an instant, she tells Harry they must go to him. NOW.

Harry calls airlines. She calls family. Grandma, Dorothy Johnston, who lives downstairs, is out bowling. Dan, their youngest son, is in class at St. Cloud State University. Oldest son Josh, an electrical engineer, lives in Chicago.

Ginny thinks her voice is calm as she repeats what the doctors said. But her family hears her rising panic. By 2 p.m., she and Harry are riding to the Minneapolis airport, saying more rosaries in the short drive than they have in 50 years.

Ginny remembers when Andy was 5 and had to go to the hospital. A car door slammed on his left hand, and rain ruined their family picnic. But on the ride home, very adult-like in his little voice, he said: "Well, all in all, I didn't think the day went too bad."

Andy sees the bright side of things. Both parents pray for a bright side this time.

But when they see him, optimism drains away.

His body is bloated, his face swollen. Both arms are raised in slings, and splotches cover his limbs, ears and nose. His breathing is labored, his pulse races, his temperature soars.

The parents gaze at their middle-born son, their Eagle Scout, their National Merit Scholar, the son who loves sports so much, who dreams of being a writer.

They try to smile and make their voices cheerful. Andy manages a "hi" before they are whisked back into the ICU waiting area.

The hospital staff had told them they'd try to hold off sedating Andy and inserting a ventilator tube until the Marsos could say hello.

They pray it's not a goodbye.

Over the next week, newspapers and television broadcasts report that the KU student battling meningitis is stable.

But in these early hours, recovery is far from certain. It's a series of setbacks and small victories. Sometimes, the bacteria hide from antibiotics, lurking behind barricades of clots. It takes three to 10 days to slaughter all the bugs.

His parents hold vigil by his side, praying without ceasing.

More relatives arrive. Dan has made the eight-hour drive with Grandma. Older brother Josh brings his girlfriend, Lori Wisniewski, from Chicago.

Each family member wishes he or she could do something to make it better. Dan asks if he could donate one of his fingers or even a hand. The doctor smiles and tells him no.

Ginny starts an Internet journal on CaringBridge.org/mn/marso. The Web site allows relatives and far-away friends to check on Andy's condition and leave notes of support. People write in prayers from as far off as Qatar. Each sentence the family reads is a balm of comfort.

KU students, Andy's friends, arrive in waves. They organize their visits into shifts. At least two students will be with Andy around the clock. It's a simple plan, and one they've used before to get good seats at KU basketball games. They just want to help.

Hope flows and wanes. One day, a doctor checks a sedated Andy's fingers and toes, telling the family the circulation is coming back. Two hours later, a vascular surgeon declares to medical students that Andy's extremities are dead. He talks of amputations and stumps.



Andy's mother, Ginny Marso, uses a purse to elevate one of Andy's stumps. It was causing him discomfort during a visit to KU Med Center.

After a week, doctors think the bacteria are dead. They begin to wean Andy off the sedatives. Then, jubilation! When a pop tune floats out of the television, a semi-conscious Andy delights them with a mini head-bop dance and the barest of smiles. He's still with them if he can act silly.

When Andy's ventilator is finally removed on May 5, his first scratchy words are "So, what's the plan now?"

He asks if anyone else got sick. No. His next request is to see Clay.

"Thanks for saving my life," he whispers.

No one can say how long Andy's recovery will take. No one knows.

Recovery from meningococemia is measured in millimeters of dying skin and healthy pink flesh. But no amount of prayer seems to halt the creep of tissue death on Andy's fingers and toes.

His doctor prepares Andy mentally by listing parts of his body that might have to be amputated; dead tissue must go. Andy calls the list his "amputation buffet."

Andy is stoic. Who needs a little ice? A few fingertips won't matter.

For hours, he stares at his hands and feet, black and shriveled. He can feel them but not move them. But his right thumb still looks the way it should. He watches it obsessively, and hopes.

His treatments are grueling routines of peeling and slicing dead and dying tissue. It takes place in "the tank room": Two stainless steel tables, tilted toward a drain, with water hoses dangling above.

The "debridements" never vary: Andy's dressings are removed, his wounds washed. Bit by bit, nurses and burn technicians remove every blackened chunk of skin, dead muscle and tendon. His wounds cover 30 percent of his body.

As music plays over speakers, Andy watches his blood and bits of himself swirl into the drain. He wants to cry out, tell them he's a fitman being, not a mannequin. But the pain is so great he cannot speak without screaming.

Sixty times he endures the hours-long debridement sessions.

Ginny can't bear to watch. Andy's pain is unrelenting.

Many nights, Andy wakes and curses meningococcal disease.

RECOVERY: After amputations, the fight to reclaim a life begins

He tells the bugs they've won. They've beat him down, cracked his soul. He gives up. He cries. Then he falls asleep. When he wakes, it's another day. Another small victory.

And then it starts over again. Andy wades through the pain, steeling himself for the shredding, the stinging.

He would bear anything to save his hands and feet.

They amputate his feet first. Just the toes, they tell him. But when the anesthesia wears off, he learns exactly what "toes" means in medical terms. The surgeon cut all the way to the middle of his arch, just beyond the ball. Even more of his right foot is gone.

See RECOVERY, A-7

Continued from A-6

It's early June. Andy has two mini feet. His first stumps.

The amputations create more wounds. The doctor grafts strips of skin from Andy's thigh and adds artificial skin. Despite a cocktail of painkillers, Andy feels phantom pain, as if his toes are on fire or being crushed in a vise.

A foam dressing cinched with Velcro wraps him from his ankles to his groin, keeping his legs still and the grafts in place. Every few hours, staff turn him to prevent bedsores. Every move brings pain.

His family agonizes with him. How much worse can this get? Every day, Gurny bargains with God to lessen her son's pain. She prays for God to spare his fingers.

Two days before Andy turns 23, the fingers on his right hand are amputated. He keeps the thumb, a few inches of flesh, bone. And hope.

The surgeon sews the stump inside a pouch of skin in Andy's abdomen. For three weeks, new skin will grow. Doctors can give him medication for the pain but nothing for the "heebie-jeebies" of having your arm sewn into yourself.

In mid-July, they take all the fingers on his other hand. The night before the surgery, Gurny Marso cries during church. She will never again see her son's hands.

Gone will be the fingers that curled around her own when he was just hours old. The fingers she held while walking across the street. The fingers once smashed in a car door.

Daily visits from Andy's friends are gifts. They bring him strawberry shakes from Dairy Queen, chocolates from Germany and meatballs from Minnesota.

They want him to be happy. Sometimes he is. Sometimes he fakes it. He doesn't want to disappoint them.

And he learns that sometimes when he fakes being happy, happiness seeps in. A few times, his friends make him laugh so hard he fears he'll rip a skin graft.

His buddies remind him there's a normal world outside the hospital. Many an afternoon they find simple joy watching "Jeopardy" and answering along with Ken Jennings.

One day, Harry asks his son if he wants anything from the store. Andy says, "Yeah, dancing girls."

For a while, "normal" seems to sit just outside the hospital doors — beyond his reach but as close as his discharge date.

That thought keeps him going through the summer.

In mid-September, he's discharged.

For weeks he'd dreamed that by fall he'd be living with his friends in their apartment, maybe even returning to work.

Instead, he lives with his parents and, faces more weeks, months, maybe years of rehabilitation. While it takes only hours to become an amputee, it takes time to fully know what that means.

Andy needs help eating, scratching his nose, brushing his teeth. His right thumb can't do everything his hand did before. Andy breaks down one night, telling his mom he could live in a wheelchair forever if only he had his hands.

His mother gently wipes his tears.

Andy's life settles into a pattern: Daily dressing changes, every-other-day therapy sessions, weekly wound inspections.

More small victories: Wearing clothes again, going out for pizza, punching numbers on a cell phone with his thumb.

In October, Andy takes his first steps in special boots, thick, heavy and chunky, weighted to balance his stumps. Walking 20 yards saps his energy. He could run again if he opted for more amputation. But whatever is cut away is gone forever. Andy chooses to wait.

In other therapy sessions, he works with his hand stumps. He picks up corn kernels with a metal scoop and pours them into another container. Andy tackles the exercise as if his life depends on it.

In a way, it does. Whatever mastery he achieves in the muscles of his arms and stumps will ease his transition into prosthetics.

And an independent life.

He learns new ways to turn on a toothbrush, use a fork, write notes. He lives for small victories now.

He asks his father to take him to the apartment he once dreamed of sharing with his buddies. One snowy night, father helps son hobble up three sets of stairs. Andy sits on the couch and they watch a little of a basketball game.

The experience stirs something fresh in Andy: a dream of living on his own.

A future he could build ... if he had the right tools.

The rubber hand looks ugly. Covered with a pinkish, squishy-rubber skin, it is free of wrinkles, hair or imperfection.

Wires dangle from the open wrist. An on/off switch protrudes below a 7.6-volt lithium battery connected to a computer chip. Electrodes carry signals from muscles in his stump to the chip. The chip sends instructions to a motor that operates the hand. Every night it must be plugged in for a charge.

It's ugly, all right. But looks don't count today. This is a practice hand.

Almost one year has passed since the bugs invaded.

The disease stole his fingers and his toes, his last three weeks of college, his first professional job and his first bachelor apartment.

It almost stole his life. Today, he gets a tiny piece back.

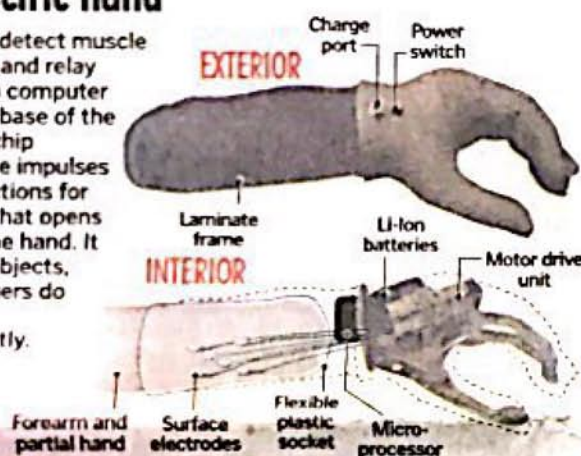


Prosthetist Steve Mandacina works on Andy's new myoelectric hand. The hand, which operates on battery power, will enable Andy to do more for himself.

Photos by TAMMY LUNGKAD/The Kansas City Star.

Myoelectric hand

Electrodes detect muscle movement and relay signals to a computer chip at the base of the hand. The chip converts the impulses into instructions for the motor that opens or closes the hand. It can grasp objects, but the fingers do not move independently.



Source: Harney Prosthetics & Orthotics Inc.

The Kansas City Star



Prosthetic options include nonfunctioning fingers for cosmetic purposes. All of Andy's fingers were amputated.

In Suite G056 of the Delp building at the KU Med Center, prosthetist Steve Mandacina pats Andy's left stump with baby powder.

"What matters is fit. Feel. Comfort," says Mandacina, twisting the rubber hand into place. It slips on with a *popfft*. White particles drift in the sunlight.

The rubber hand sticks out four inches farther than a normal hand, as if Andy has two wrists.

Like a tailor fitting a suit, Mandacina dabs little x's with a marker where the hand's socket is too loose or too snug, or where it needs better contact with a muscle.

Too loose and Andy risks embarrassment if it flies off at an inopportune moment. Too tight and frustration could mount when Andy struggles to take it off.

Mandacina takes the hand to a nearby lab to be pinched and glued, measured and cut.

Andy tries on the hand over and over for two hours. Finally, the socket is as comfortable and snug as an old shoe. To keep the electronic guts inside the hand, Mandacina wraps it with several loops of electrical tape.

Ugly.
And beautiful.

The only noise in the room is the whine of a weed trimmer just outside the open window. "Go ahead, Andy," Mandacina says.

Andy stares at the hand, his lips drawn tight into a thin line. He remembers how it feels to press his thumb and pinky finger together.

And the hand moves.
Open. Close. Open. Close.

His wrist quivers, but Andy doesn't stop.

At first, the hand opens and closes fast. Andy develops more technique. The hand ratchets open in increments.

O-o-o-per!

C-1-1-lose

Andy looks around, searching for an object to hold. Something to put this new hand to work.

"Dad, hand me the bottle."

Harry Marso gives Andy his almost-empty soft drink bottle.

Just the action of placing something in his son's hand brings a smile to the corners of his mouth.

The fingers grasp the bottle.

Across the room, Ginny Marso leans forward, holding her breath.

All eyes are on Andy as the bottle of Minute Maid Pink Lemonade slowly rises towards his lips — lips now smiling wide.

But at the crucial moment, the bottle drops.

Andy tries again, raising the bottle slowly. Again, it falls.

The third time, as the mechanical hand rises, Andy turns off its switch with his right thumb — the thumb that survived the bugs, the thumb that stayed alive. The hand freezes in its grasp, holding the bottle tight.

Andy drinks

He looks at his parents, who are grinning, thrilled. They have been through so much with him, sitting at his side, praying over him, feeding him, talking to him long into the night when he couldn't sleep.

They know their son can do anything he wants to do. He has the courage, the will.

Sometime in the next few months, they will take Andy home to St. Cloud and try to resume their lives.

The move to Kansas City has cost Ginny her law office, and Harry's leave of absence has grown longer and longer. Ginny works nights now at an IRS office. The family's savings are dwindling.

The Marsos have stayed with Andy for a simple reason: He needs them. He faces more surgeries, more therapy, over months, maybe a year.

Through his family, Andy says, he has learned that "unconditional love is real." He's lived it.

"The fact that there are people who are willing to completely put their lives aside, and do whatever they can, no matter how small it is, just to ease your suffering..." His voice trails off.

He grieves for what is lost, even as
he reaches for what comes next.

He looks at the \$20,000 prosthetic hand. It can't feel a basketball's texture. Its fingers can't dance-on-a-computer keyboard. It *must* be plugged in nightly to stay charged.

"It's just a tool," he says.

Beautiful.

And ugly.

But another small victory.

One he can hold tight.

To reach Lee Hill Kennel, call (816) 234-4420 or send e-mail to dkennel@krstar.com.

MENINGOCOCCAL DISEASE: THE FACTS

What is meningitis?

An infection of the fluid of a person's spinal cord and the fluid that surrounds the brain. It's usually caused by a virus or a bacterium. Viral meningitis often will clear up on its own. Bacterial meningitis can result in brain damage, hearing loss or learning disability. The fatality rate for bacterial meningitis is 3 percent to 11 percent.

What is meningococcemia?

Like meningitis, it's a form of meningococcal disease — but the most severe form. The bacteria poison the blood. The fatality rate for meningococcemia, even with medical aid, is 40 percent.

What are the symptoms?

Many are flu-like; sudden onset with fever, intense headache, nausea and often vomiting or rash.

How many people get bacterial meningococcal disease each year?

In the United States, 2,000 to 3,000. It kills about 300 each year. Missouri reported 20 cases last year and three deaths; Kansas reported 15 cases and three deaths.

How do the bacteria spread?

Through coughing, kissing and other exchanges of respiratory and throat secretions, and in crowded living conditions such as a household, overnight summer camp, military barracks, college dorm or day-care center.

The bacteria that cause meningococcal disease are not as contagious as the common cold or flu, and they are not spread by casual contact.

Is there a vaccine?

Several vaccines protect against four of the five serogroups that commonly cause meningococcal disease: A, C, Y and W-135. There is no vaccine for serogroup B because those bugs have an outer coating that mimics human cells. Serogroup B accounts for 30 percent of U.S. cases and is the type that infected Andy Marso.

Scientists think a new vaccine, Menactra, approved in January by the FDA, could provide immunity for up to eight years. Menomune provides immunity for three to five years.

Who should get the vaccine?

Anyone can get meningococcal disease. Some groups are particularly at risk.

The American College Health Association recommends that all college students get the meningitis immunization. Most universities, including those in Kansas and Missouri, require entering freshmen to either get the vaccine or sign a waiver declining the shot.

Others who should get the vaccine include military recruits, travelers to high-risk areas such as sub-Saharan Africa, anyone with a damaged or removed spleen, people with an immune system disorder and those who might have been exposed to meningitis during an outbreak.

Children should get the shot at their routine preadolescent visit (at 12 years of age). Infants should be protected by the Hib vaccine, which is routinely given by pediatricians.

Where can people get the vaccine?

County health departments provide the shots. Vaccination costs about \$100.

Sources: U.S. Centers for Disease Control and Prevention; state and county health departments; American College Health Association



Easter brought the Marso family together for a prayer and dinner at their apartment in Mission. Clockwise from left: Andy, Dan and Harry Marso; Lori Wisniewski; Josh Marso; Dorothy Johnston; and Glenny Marso.



With his mother watching proudly, Andy uses his new hand to maneuver his wheelchair out of the prosthetics office at K11 Med Center.