

## *“What Makes Caregiving Rewarding?”*

### **2008 Story Contest Winners**

Shield Healthcare is pleased to announce the winners of its 8th annual caregiver story contest!

Through this contest, Shield Healthcare is presented with a special opportunity to hear the voice of exceptional people, who have played a dedicated role in the lives of loved ones or patients with special needs. With more than 300 touching stories to choose from, the selection of our winners was given the utmost consideration. Sincerest thanks to all who shared their personal stories.

We have included a copy of the winning stories in this newsletter for your reading inspiration.

***Congratulations*** to our winners,

selected by Sandra Mitchell, CBS 2/KCAL 9 News Anchor



### **Our Grand Prize Winners**

**Nicole Lugo** of Whittier, CA

**Susan Agrawal** of Chicago, IL

**Angela Oberg** of Apple Valley, CA

### **Our Runner-Ups**

**True Gallegos** of Denver, CO

**Liana Gonzalez** of Ontario, CA

The three grand prize winners received \$1,000 in American Express Gift Checks, a commemorative plaque, and an annual subscription to *Today's Caregiver Magazine*. The 2 runner-ups received \$250 in American Express Gift Checks and an annual subscription to *Today's Caregiver Magazine*.

All contest entrants will receive a commemorative, “I Care” heart lapel pin.

#### **Shield Healthcare**

Chicago 800-675-8847	Denver 800-585-8049	Fresno 800-675-8842	Los Angeles 800-372-6205	Inland Empire 800-557-8797	Sacramento 800-675-8842	San Diego 800-557-8797	San Francisco 800-675-8840
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#### **Medical Supplies for Care at Home Since 1957**

## *“What Makes Caregiving Rewarding?”*

Grand Prize Winner 1

By Nicole Lugo Whittier, CA



The hands on the clock are moving, but sitting here, the minutes seem to drag on. I can hear the subtle hum of the florescent light, one of the only noises to fill the room. The floor is cold, grey, and uninspiring. In fact, the entire room is bleak and cold, a pale white with only a few splashes of color to break the monotony. I have been sitting in this chair, stiff and uncomfortable, for hours, days...weeks maybe. In here, time escapes you, drips away like an IV drip. I have lost any sense of the outside world, but in reality, that doesn't matter. My time here is precious; my most valuable gift. Her hand moves slightly, probably not by her own accord but reflexes. They too, are cold and slightly grey. Years of fighting and struggling show on her right hand but her hand is at peace right now. There is nothing for it to do but lay there. I've touched that hand hundreds of times and it is usually warm and soft. Today, it's cold, dry, and calloused.

As I sit there, I find myself staring at her hand...that hand, wondering about all that it has seen, touched, felt. It, like a book, can tell stories and describe precious memories. But not today, not yesterday, and probably not tomorrow either. I look down at my own hands, 40 years younger and wonder what they will look like, what stories they've yet to live through and if someone will look at my hands and wonder about their history. I don't know how long I've been staring at her hands, but I finally catch myself and realize I've been in a trance of sorts. My eyes look up, and see her lying there, motionless still. Her face is sunken and worn. At one time her face was warm, colorful, and alive. Her cheeks were once vibrantly red, plump, and loving. But not today, not yesterday, and they won't be tomorrow. Her lips are a very pale pink, dry, cracking. I wonder how long its been since they've been kissed, told a joke, or even cracked a smile. Today, it seems as though even a smile would be a miracle. In fact, the only color to her is the vibrantly red and purple scarf she wears over her head. This small piece of cloth is the only thing to bring color back to her, yet it hides one of the most upsetting facts about life: she has lost all of her hair. The chemo has stripped her of the long, golden hair she used to have. It is a terrible side effect of the powerful treatments. Still in most patients' eyes, they are willing to sacrifice their hair for a chance to be healthy again. It is an unfortunate sacrifice, one that will linger on long after she leaves here. And then her big blue eyes open. They are impossibly blue, almost unreal. They look around, dazed and confused. Her eyes dart, but her head doesn't move. I can see now that she knows where she is. She has awoken from a beautiful dream and now reality has hit. She remembers where she is, and why she is here. She finally sees me, and smiles. It is a painful smile, but a smile nonetheless. That is today's victory.

She motions for me to come near, as her words can barely escape. She doesn't have the strength to talk, another sacrifice of the chemo treatments. I gently lean over her. She asks how long I've been here. "Hours, I think. I'm not really sure." It takes a moment for her to grasp what I said. Her eyes are sharp, and never leave mine. "Oh" she said, "don't you have anything else to do?" I quickly remember my own reality: bills, appointments, TV shows, school, life. "No" I said, "nothing is more important than you, here, getting better." Her eyes quickly squint as another smile came thru but this one was vibrant, alive, and painless. "Thank you. If it wasn't for you, caring so much, I would have given up my fight a long time ago." My heart jumped thru my scrubs. Tears fell softly down my cheek. I grabbed her hand, gently squeezed it, and said the only thing I could think of: "Thank you. I love you." There, captured in that moment, is the reason for my calling. I am a nurse to comfort, to hold, to inspire. I am a nurse to repair broken bones, broken bodies, and broken dreams. I am a nurse to remind people, in their most desperate and vulnerable moment, that life will improve. I administer medicine, but most importantly, hope.

Can there be anything greater than that?

## *“What Makes Caregiving Rewarding?”*

Grand Prize Winner 2

By Angela Oberg Apple Valley, CA

When my youngest son Alex was four years old, eighteen years ago, my role of caregiving began. The day he was admitted into the hospital I felt I was too. I slept at the foot of his bed and would not accept the fact that the doctor's had given up all hope of recovery. My husband and two other children had to learn to take care of themselves while I focused all of my attention on Alex. After a six-month stay we came home with Alex brain damaged, but he was alive and responsive. We had the miracle no one thought was possible. It was devastating, as you might imagine, but I was determined to make him well again. He learned how to walk and talk; however he was consumed with intense behaviors that made normal family life impossible. We persevered as a family. Alex's behavior made it difficult for him to go to school independently so for years I went with him as his aide. I fought the school systems for appropriate placements. I fought hard because Alex loved school and I loved how happy it made him to go.



At age sixteen Alex became very sick with a bacterial infection that was misdiagnosed despite all our attempts to show the medical staff that he was very, very ill. He became Septic and from that point forward everything changed. He cannot walk, talk, eat, express his needs, wants, discomfort, anything. He requires 'round the clock care for feeding, changing, and monitoring his breathing by video monitor, even overnight. Alex weighs over 200 lbs. and has to be moved by Hoyer lift a minimum of four times per day by his Dad and I.

When people ask me “how do you do that” or say “that must be so hard” I think the hard part is for Alex, who cannot walk to the kitchen and get himself something to eat, or go to the bathroom without my assistance. It is Alex who has the challenge of trying to express his needs with no form of communication. It always surprises me that people focus on my role of caring for him, instead of seeing that the hard part is on Alex. While being his caregiver might not be easy, my life would be empty without him. Every time I get the “break” I think I need I am anxious to get back to Alex and make sure that he is okay. Alex is a fighter and will always be my hero. We will never give up on him.

But the one thing that hasn't been taken away from Alex is his ability to show love. Every time he smiles at me or I see that spark in his eye of remembrance when I say something that is familiar to him it makes it all worthwhile. That is something that he would not express if he lived in a place when he was only physically cared for and not loved as he is by his family. Alex's family is the only thing that brings him any joy. That is the reason that I do this, for him, so he can hold on to the one thing that he has left. He has been robbed of everything else in his life and this is the one thing that I can give to him that means so much to him, love and care by his family. Even though it can be incredibly challenging at times, since Alex is basically housebound due to his fragile medical state, we make it work. We build our lives around Alex instead of trying to have a life and fit him in. His dad and I will always care for him and would not have it any other way.

Alex has taught me so much that we have now opened our home and became foster parents for special needs children as well. Whether it is children with Autism, emotionally disturbed, or developmentally delayed, I enjoy teaching them what Alex has taught me: Patience, Acceptance, and Unconditional Love.

## *“What Makes Caregiving Rewarding?”*

Grand Prize Winner 3

By Susan Agrawal Chicago, IL



### Every Little Inchstone

Today my five-year-old daughter lifted up her fragile hand and placed it on my arm. In most families, such a subtle gesture would not be noticed, let alone celebrated. But for my daughter Karuna, who has severe Cerebral Palsy and several other medical conditions, moving her hand to express her love for me is a momentous task requiring every ounce of her concentration. It is also today's "inchstone."

Parents always celebrate their children's milestones. There are those tentative early steps, the first utterance of "Mama," and major life events like graduating from high school or getting married. As is the case for many children with special needs, these milestones may never occur for my daughter due to her physical condition and poor prognosis.

I could let this unfortunate truth- this lack of achieved and personal milestones- drag me down into a state of hopelessness. Instead, I choose to celebrate "inchstones," those tiny little milestones no bigger than an inch but every bit as significant. While seemingly trivial, these daily events show me that my daughter is in fact living, surviving, and thriving. Today it is lifting her arm. Tomorrow she may vocalize her excitement. Perhaps another day she will use her communicator to tell a joke. Some days it is just making it through an evening without needing oxygen.

Every little inchstone gives us a chance to celebrate her accomplishments, no matter how small. Sometimes the celebration is little more than a hug, while other times it is photos and videos e-mailed to all our friends to demonstrate just how proud we are of Karuna. Inchstones have taught me the power of recognizing the positive in every day, not allowing the day-to-day struggles that we all experience to take over my thoughts. They have helped me to see value and accomplishment in the smallest of movements, the tiniest of steps, or the most miniscule achievements. They act as a positive force carrying me through each day, especially on those days when everything goes completely and utterly wrong.

There are definitely days, especially those days spent holding a screaming child or praying over a child fighting for her life- when it is difficult to unearth even a drop of happiness. During these times, the worst of the worst, I force myself to take a moment and jot down an inchstone or two. Inchstones bring a smile to my face and create a moment of joy in an otherwise bleak day.

Had I not learned to celebrate inchstones, surviving all of the tough times I have experienced as a caregiver would have been immeasurably more challenging. Among all the blessings that my daughter Karuna has bestowed upon me, seeing her grow through inchstones has granted me the best gift of all: the ability to see wonder and joy in the most unexpected places.

## *“What Makes Caregiving Rewarding?”*

By True Gallegos Denver, CO

1st Runner-Up

We have the honor of being able to care for our 26-year-old son, Joseph (Joe Joe). He has Cerebral Palsy as a result of being born almost 3 months premature. He can't walk or talk and he must be on oxygen all the time. He used to be able to eat regular food, but last year it was determined that he was swallowing food into his lungs. He developed pneumonia and we almost lost him. Now he must be tube-fed.



Joe Joe requires 24 hour day care. His dad, Phil stays up with him all night and I do the day shift. Joe Joe brings out the best in everyone around him. He has had to suffer what most people would consider unbearable, every day. Yet even on his worst days, he has a radiant smile. Sometimes I'll find myself grumbling or worried about things that really don't matter and I will see his smile or hear him laugh, and I tell myself that if he can go through life with a cheerful attitude, why can't I? He is the only person that has a right to complain about anything, but he doesn't.

He has his bad days, heartbreaking with the pain and agony that his life is and on those days it would be so easy to fall into a deep depression, but he doesn't. He manages to greet everyone who comes in contact with him with his own way of hello and a smile. He tells his family "thank you" or "I love you." He is always ready to go for a ride, it doesn't matter where. "We go yet?" is his favorite thing to say.

Joe Joe is a huge sports fan, especially the Denver Broncos. We have a family tradition of watching games together. He has a stuffed hobby horse that when its ear is squeezed, it plays a galloping sound and different songs. When the Broncos score a touchdown or do something good, it's Joe Joe's job to "ride the horse." He loves this! A recent memory I have is of the Broncos scoring a touchdown, the horse going off and of Joe Joe laughing and laughing, even though seconds before the score he threw up.

People mean well and say they admire Phil and I for taking such good care of Joe Joe. There is nothing special about us. We are a mom and dad who are devoted to their son, as we are to all of our kids. It is Joe Joe who is to be admired. The only time he wasn't cheerful was when he was in a chemically induced coma and on life support. He is the bravest person we have ever known. His weakness gives us strength. Phil and I consider ourselves truly blessed to do what we do; what we were born to do every day. Many people think that they never do or say anything wrong and that they are perfect. How fortunate we are to be able to care for someone who actually is perfect.

## *“What Makes Caregiving Rewarding?”*

By Liana Gonzalez Ontario, CA

It was the Spring of 2004 when we heard the horrible news: “Your mother has suffered a major stroke as a complication of her surgery.” We had known there would be risks. Brain surgery is something that even the most optimistic can’t help but take pause. But a stroke... as the reality sunk in, I became numb. Then, the questions began to tumble through my brain. Why? Why now? What went wrong? She’s too young for this! I’m too young! She was supposed to get better! To be honest, those thoughts have never completely gone away. I know now that the mindset of a caregiver is unique amongst all others. Suddenly it was no longer about me, but about what I could do to help her. The questions kept coming. What education did I need? What changes would we have to make at home? What were her care needs? What if I made a mistake? Ever so slowly, I learned how to seek and find answers to my questions.



When my mother opened her eyes for the first time the next day, she looked at me as though she were staring at a stranger. We couldn’t understand a word she said as she was very aphasic. But as time went on, we caught a word here and there, then a phrase, then a sentence. Little by little, the answers to my questions would evolve with the small accomplishments of the day. I learned to adapt, I learned patience, and I felt joy. I nearly cried the day I got her to take a bite out of her favorite Arby’s roast beef sandwich!

As it would happen, I was in college and about to end the school year for summer break. I had planned to get a job to help make ends meet, but this was so much more important. I took the summer off and I was there everyday, managing medication, giving injections, dressing her, applying her makeup (that had always been important to her). I shopped and took her to medical appointments and did home therapy. We counted change together, learned how to use the telephone, how to tell time, the difference between shampoo and conditioner. It’s amazing how much we take for granted, we in our warm little cocoons of ignorance. I learned gratitude for the things I have.

Today I can safely say that my mother is continuing to make a wonderful, even miraculous recovery, and as for me, I was inspired to enter the field of medical social work. I’ve since obtained a master’s degree, and my graduate research study was dedicated to my mother. I now work in a large hospital helping families to answer those very same questions about caregiving and coping that I had from day one. The skills that I acquired through caregiving, the lessons I learned, are put to use everyday. And along with my loving family, I continue to help my mother with her needs.

The most rewarding part of being a caregiver is the change it’s made in me. I was blessed with the opportunity to touch a life, to give of myself, and I am able to bring that helping spirit to now touch others. I wish I could say that I end each day with that warm, fuzzy feeling. I don’t. I wish I could say I’m able to give, give, give without time for myself and find my complete contentment in the work that I do. I can’t. But what I can say, beyond a shadow of a doubt, is that I have loved. Love is a choice. And by the Master’s design, it is meant to be expressed to all. So I will continue to love, to hope, to live, and to reach out to whoever might be reaching back.