By Susan Sarver

Moving On

In 1994, **MELISSA SAMMONS HUGHES** was diagnosed with lupus. Since 1997, she has been unable to return to medical practice as a pediatric hospitalist, even after aggressive chemotherapy and eight surgeries that included joint replacements for both hips and both shoulders. "It was a major loss," she says. An auto accident in February, 1998 killed his wife and best friend instantly and left **GREG SOBCZAK, MD** with major injuries and unable to walk. "When I woke up," Sobczak recalls, "I didn't want to live." **CLAUDIA OSBORN, DO** sustained a severe head injury in a bicycle accident twelve years ago, preventing her from returning to her internal medicine practice in Detroit's inner city. "I defined myself as a physician. It was very much my life's work and the loss of that was a devastating blow," Osborn recalls. **FRANK DELEON-JONES, MD** experienced the initial symptoms of amiotrophic lateral sclerosis (ALS) in the summer of 1993. By year's end, his right arm was weak and his left arm was beginning the same cycle. DeLeon-Jones believes it is important to "feel challenged and gather the energy and self-esteem necessary to overcome the barriers."

Physicians find disease and disability ultimately can lead them to new ways to use their medical training.

LESSONS IN LIFE FROM FOUR COURAGEOUS DOCTORS.

Given that the knowledge of medicine confers a degree of power over illness, it would seem only right that exercising that knowledge to heal others should afford some degree of immunity to disease and disability. But of course, that isn't the case, as Atlanta pediatrician Melissa Sammons Hughes found out.

"I think physicians sometimes think that they're invincible, that they're not going to get sick," says Hughes. Giving birth to twin daughters and a son while in medical school and later managing home and family amid the 60- to 80-hour work weeks demanded of an early career in medicine did nurture a sense of "superwoman" power in Hughes. By age 35, she had snagged her dream job as a pediatric hospitalist at Children's Healthcare of Atlanta at Scottish

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Rite, providing care for children with serious, often rare diseases. She was the type of physician who spent time with her patients and sat and talked with parents. "I absolutely loved what I was doing," says Hughes.

Soon after she took the job in 1994, Hughes was diagnosed with lupus. Because of neurologic involvement which made it difficult to walk, she underwent an aggressive course of chemotherapy, which she continued even after returning to work. Then one November day in 1997, she spiked a fever, grew lethargic, and had to be admitted to Emory University Hospital. "From that point on, my life changed," she says, "I had bone marrow failure and a real life-threatening illness at that point." After six weeks of treatment and another six months of recovery, she again went back to work. Three months later, she discovered that avascular necrosis, which was likely caused by the Prednisone prescribed to keep the lupus in check, was eroding her joints. After eight surgeries that included joint replacements for both hips and both shoulders, Hughes began to lose hope of returning to work to care for sick children, particularly in her immuno-compromised state. Since 1997, she has been unable to return to medical practice. "It was a major loss," says Hughes.

Still making a difference

The need to accept change and move forward with a disability is no easier for physicians than for any of the other nearly 49 million disabled Americans.

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Evaluating Your Disability Insurance Policy

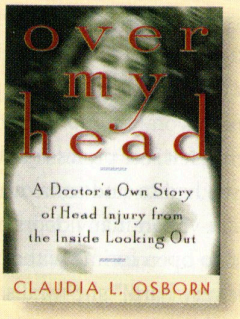
"The largest asset a person has is their ability to earn [an income] every day," says Terri Eilers, the assistant sales officer of product management and sales at New England Financial. When evaluating disability insurance, Eilers offers these points:

- **CONTRACT TYPE—Non-cancelable policies are those in which premiums remain the same. Guaranteed renewable policies have premiums that may increase. Neither can be canceled providing the premiums are paid.**
- **DEFINITION OF TOTAL DISABILITY—A strong definition has three parts:**

  1) You are unable to perform the duties of your occupation due to accident or sickness. 2) You are not working in another occupation. 3) You are under a physician's care.

  'Own Occupation' riders remove the second part of the definition, permitting benefit qualifications based on inability to perform duties of your own occupation.
- **BENEFIT PERIOD—Should extend to age 65, if born before 1960, or age 67, if born after 1960, based on average retirement ages.**
- **RESIDUAL BENEFIT COVERAGE—Provides a portion of your monthly benefit if you lose part of your income due to disability. This coverage should extend through the full benefit period.**
- **ELIMINATION PERIOD (Waiting period before benefits begin)—A six-month period is more cost effective provided you have savings enough to get by during the elimination period.**
- **BENEFIT RESTRICTIONS—Be aware of benefit restrictions on mental, nervous, drug and alcohol-related disabilities. Appraise policy according to your own potential need.**
- **COST OF LIVING BENEFIT—An important rider that automatically inflates the benefit at periodic intervals, however, with a benefit period of age 65, buying such a rider after age 50 or 55 is less cost effective.**
- **FUTURE INCOME OPTION—An important rider that allows you to buy additional insurance in the future without going through medical underwriting, providing you have sufficient income to qualify for more benefit.**
- **BUILT-IN WAIVER PREMIUM—A good contract includes the waiving of premiums after 90 days of disability.**
- **CONCURRENT DISABILITY DEFINITION—Period of time that determines the need to re-qualify for an elimination period—12 months is more lenient and preferable than 6 months.**

Eilers also advises to pay your premium with 'after-tax dollars' so your benefit is tax-free. On pricing, a good rule of thumb is two to five percent of your earned income for a policy that replaces no more than 60 percent of your net income. ■



Claudia Osborn, DO wrote a book about recovering from the brain injury that took away her ability to practice medicine: *Over My Head: A Doctor's Own Story of Head Injury from the Inside Looking Out.* Though it was a seven-year endeavor, Osborn's book helped lead her in a new direction. She now lectures extensively, addressing therapists, physicians, associations, and service organizations.

Osborn believes there are three primary forces that make a difference in recovery from brain injury: quality rehabilitation, assistance from as many people as possible, and motivation. **"I don't find many physicians who don't have a strong sense of internal motivation," she says.**

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In fact, in many ways, it may be more difficult. For physicians, coping with the loss of or reduction in the capacity to participate in a profession that so deeply defines them can be especially challenging.

Hughes felt lost professionally and knew she had to find some way to apply her skills. "I had many doors that seemed to open for me without having to look very hard," she recalls. Hughes began volunteering as a medical adviser for the Atlanta Day Shelter for Women and Children, helping to organize a range of health services and establishing a protocol book on managing children's symptoms in the shelter. She started to serve on the PTA board at her children's school, taking the lead on its drug awareness program, and she took hold of her church's youth health ministry, helping to develop parent forums to discuss drug and sex awareness to keep the congregation's 1,100 young people safer in the community. Hughes even started a lupus support group that has grown into the largest in the state. She has learned to pace herself by delegating duties, and she maintains a back-out plan in the event that she is unable to lead a meeting or give a talk.

For many physicians, keeping alive the hope of returning to medicine is an integral part of moving on in their lives with a disabling condition. Hughes keeps her knowledge up to speed by reading journals and fulfilling continuing medical education (CME) requirements. She also keeps her board certification and licensure current.

Greg Sobczak, MD of Norton Shores, Michigan, will also be pursuing CME courses this winter in the hopes of one day practicing medicine again. While on his way to Savannah, Georgia with his wife, his best friend and the friend's wife, the family practice physician was involved in an accident. Without warning, a trailer went up on two wheels, rammed into their vehicle and sent it into a tumble, ejecting all four passengers. The February 1998 accident killed his wife and best friend instantly, and Sobczak barely escaped with his life.

It took him nearly 12 weeks to become fully alert. "When I woke up," Sobczak recalls, "I didn't want to live." In addition to coping with so many losses in his life, Sobczak had to figure out how to get around again. A fractured pelvis and damage to the cauda equina left him unable to control his right leg. With encouragement from his five chil-

dren, three stepchildren, friends, and even a few patients who slipped past the "family only" visitor restrictions, Sobczak found the strength to begin the long journey through rehabilitation. There were many painful moments, says Sobczak, recalling his first attempt at ambulation, which resulted in hyperflexion of his knees. After spending five and a half months at two different rehabilitation facilities, Sobczak was able to get around by alternately using a wheelchair and walking with two crutches.

The mobility limitations have been especially challenging for Sobczak. He had always enjoyed walking. Up until the accident, he walked five miles a day in addition to providing care for 30 or more patients per day. He is now in charge of his own therapy and is dealing with lingering paralysis in his right leg from the knee down and partial paralysis of the left leg with foot drop; yet, he has made gradual progress. "I'm able to walk with a crutch or a cane," Sobczak says. At home, he walks near walls and furniture for support, and he is able to drive with the aid of a left foot accelerator. This level of progress has been hard won, however. Without the ability to determine the exact placement of his right foot, Sobczak fell and fractured his right ankle a little more than a year ago. His focus now is on building up endurance. "I can walk a few hundred feet before I have to sit back down and rest."

After the accident, the 10 other physicians in his Muskegon family practice group, which Sobczak helped to form in 1984, were able to take over the care of his patients. Because of his ambulation difficulties and the full-time commitment required by the hospital that purchased the group two years before the accident, Sobczak has been unable to return to his practice. He often runs into his patients out in the community, and they are quick to let him know that they'll be back if he is able to return to practice. He misses the patient contact. "I never looked at it as a money-making profession," he says, "I enjoyed working with patients...talking. My patients basically were my friends."

He currently teaches anatomy and physiology in a local college two days a week, but he finds he needs his days off to recover from the exertion. Sobczak's way of caring about his students and listening to their problems reflects his style of practicing medicine. He enjoys the opportunity to help, "but it's not as con-

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centrated," as in medical practice, he says, adding, "I still miss the fun of medicine."

Focusing on strengths

Focusing on developing residual strengths and abilities after a life-changing illness or accident can sometimes create a path that leads in a new direction. "Anyone who has a significant brain injury has a great deal to overcome," says Claudia Osborn, DO, an associate clinical professor of medicine at Michigan State University's College of Osteopathic Medicine and the author of *Over My Head: A Doctor's Own Story of Head Injury from the Inside Looking Out* (McMeel, 1998). Twelve years ago, Osborn sustained a severe head injury in a bicycle accident, preventing her from returning to her internal medicine practice in Detroit's inner city. "I defined myself as a physician. It was very much my life's work and the loss of that was a devastating blow," Osborn recalls.

Yet, Osborn had more than her professional losses to deal with. After brain injury, "there are so many basic skills you have to learn," she says. Osborn says she had no memory of being injured and only a dim recollection of the nine months preceding her rehabilitation.

She spent a year and a half in the Head Trauma Program at New York University, during which she worked to regain her lost cognitive skills and overcome the apraxia that affected her right arm, causing it to move like "a crane operated by a drunken five-year old." It was particularly difficult to watch rehabilitation videotapes and see herself as inarticulate and unable to function productively when she remembered being a dynamic physician.

Amid her grief, she came to realize, "In brain injury, you don't make much progress if you don't gain a real acceptance of your new ability," she says. "You've got nothing if you stay in that no man's land of not moving forward. It's a sort of changing of your lenses, so that you can create new dreams for yourself." To begin, she focused on her strengths, on what was working, and on what would help re-build her ego. For Osborn, those areas were writing and teaching

With the help of friends, Osborn was able to return to teaching nearly three years after her injury. It was a position without an income however, since physician-faculty salaries at the Michigan State University are generated through their medical practices. As Osborn began writing her book, she discovered that the process itself was therapeutic on several levels: rebuilding language skills, permitting emotional catharsis, and forcing her right hand to work alongside the left through the action of typing. Because Osborn says brain injury can easily result in isolation for the victim, she intended for her book to serve as a bridge between the brain-injured community and the rest of the world. Though it was a seven-year endeavor, Osborn's book helped lead her in a new direction. She now lectures extensively, addressing therapists, physicians, associations, and service organizations.

Osborn believes there are three primary forces that make a difference in recovery from brain injury: quality rehabilitation, assistance from as many people as possible, and motivation. "I don't find many physicians who don't have a strong sense of internal motivation," she says.

Fueling determination

For some physicians, past achievements, family, friends, and personal beliefs fuel the determination to move

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ahead. "The fundamental factor that allows us to overcome barriers in our daily life and work is determination," says Frank DeLeon-Jones, MD, a professor of psychiatry at UCLA and the director of the psychiatric inpatient service at the UCLA Medical Center at Olive View. In negotiating the barriers of disability, DeLeon-Jones believes in the importance of "the willingness not to see oneself as a victim or misfortuned, because such a posture undermines one's self-confidence," but rather, to "feel challenged and gather the energy and self-esteem necessary to overcome the barriers."

DeLeon-Jones experienced the initial symptoms of amyotrophic lateral sclerosis (ALS) in the summer of 1993 while dining with friends. As he lifted his glass, he felt surprised and perturbed by a slight tremor in his right hand. The symptoms progressed, and by year's end, his right arm was weak and his left arm was beginning the same cycle. With a medical conclusion of a cervical vertebrae lesion in May 1994, DeLeon-Jones underwent surgery. By May 1995, DeLeon-Jones recalls, "I was completely paralyzed and required another surgery because I could not breathe." He spent the next year hospitalized.

Each phase of ALS has demanded adaptation, says DeLeon-Jones. Yet, he explains there is no brief formula for adapting to overwhelming tragedy. Holding onto a lifetime of accomplishments has provided encouragement. The eldest of four children, DeLeon-Jones recalls his parents' inspiration and encouragement to pursue knowledge and cultural interests, which led to personal and professional success both for himself and his siblings. Such achievements, as well as the relationships he maintains with his parents, wife, and children all serve as important inspirational factors. DeLeon-Jones has seen these elements at work when helping others cope with ALS.

Many of DeLeon-Jones's professional achievements grew out of his strong interest in the biological and psychological aspects of human behavior. His research related to the chemical aspects of behavior has contributed to the understanding of the role of norepinephrine in the affective disorders, depression and mania, as well as in drug abuse and alcoholism. Parallel to his research, DeLeon-Jones also maintained a psychoanalytic clinical practice.

Since ALS, DeLeon-Jones continues to work in an administrative capacity on a full-time basis. He communicates with his assistants, who are available 24 hours a day, through eye blinking to convey messages and indicate letters of the alphabet in order to spell-out words. He also uses a DynaVox, an augmentive communication device that resembles a laptop computer, which responds to infrared light signals triggered by the motion of his finger. The device can print documents and speak the text that is created, enabling DeLeon-Jones to deliver presentations and interviews.

DeLeon-Jones sees the medical profession existing not only to provide proper care, but also to build self-esteem. He says that self-esteem, combined with the energy drawn from the personal inspirational components, is vital to overcoming barriers.

A supporting network

Despite the cause or degree of disability, a network of support can make all the difference. For DeLeon-Jones, the determination to transcend barriers is energized by the important relationships in his life. Osborn tributes her family for helping her to recognize and develop her residual strengths. She also relied heavily on her mother's skill in organiz-

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ing notes to write her book.

Hughes has a mutually beneficial arrangement with a Brazilian couple that lives with her and assists with household tasks and errands while they move through the immigration process. She also draws strength from her faith. "My religion is very important to me, and I actually think my faith is what has gotten me through this difficult time."

With Sobczak's long standing connection to his community, there wasn't a church in Muskegon that didn't have well-wishers offering up prayers after his accident. However, one friend, in particular, took the time to really push Sobczak in his rehabilitation efforts. "You really never know the depth of friendship," he says.

In addition to a network of human support, financial resources are critically important. "I think that disability insurance is invaluable," Sobczak says, adding that he would have experienced financial disaster without insurance. (See the sidebar "Evaluating Your Disability insurance Policy" on page 38)

Fortunately, while in private practice, Hughes had purchased a disability policy that paid 60 percent of her income. She maintained that policy even after going to work for an organization that provided one. "When you pay for disability policy yourself," Hughes points out, "the income is non-taxable. There's a big difference."

Osborn regrets not paying her insurance premiums herself, with after-tax dollars, to avoid having her benefits taxed. Although writing and lecturing are satisfying, they aren't lucrative, so Osborn must rely on those benefits for support.

Financial issues aside, without exception, a physician's emotional and physical journey following a significant change in health status is not easy. Yet, Osborn believes, "I think you do have to maintain a sense of hope. No one really knows how far you can reach as an individual. No matter what one's disability is, you have to make that effort to reach out toward something else in a creative way. I think there has to be a certain amount of belief in yourself and a tremendous sense of patience and humor. You're not going to get there quickly." ■

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