

RUSH Epilepsy Center
Chicago, Illinois
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Remarks by First Lady Hillary Rodham Clinton at
RUSH Presbyterian St. Luke's Medical Center
Chicago, Illinois
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Thank you very much, Lee Ann. Thank you for your willingness to come and share your story and speak for so many other parents of children with epilepsy and so many adults as well. I think it was apparent to all of us as we listened to you that your courage and determination in the face of what you described as heartbreak is just one more call for why we are here today and why we need to be as focused and persistent as possible in meeting the challenges posed by epilepsy.

I want to thank Congressman Davis for being with us and for his support on so many fronts that are aimed at, and are actually improving, the lives of people here in Chicago and Illinois and across our country.

Dr. Henikoff, thank you for giving me the tour that we had together in your neurology unit seeing the Epilepsy Center. I want to thank Dr. Michael Smith, who is the director of the epilepsy unit, for being with me and for explaining and answering many of my questions.

I'm delighted that Jeane Carpinter, president of the Epilepsy Foundation of America—and herself someone who can speak with firsthand knowledge about epilepsy—who was able to come from Washington to be with us. And I just had the opportunity to meet with some other people who have stories to tell as well. Before I came in, Dr. Smith and I spent some time with Mrs. Axlerod, a friend of mine. She and David have been friends of mine for a number of years, and they are parents of a child with epilepsy. And Susan is the president of CURE, a group that is committed to raising both awareness about the need for research and funds for research on epilepsy.

I want to thank Sharon Dachrow (phonetic), who was at the roundtable discussion and who has a success story to tell us about having surgery here at this hospital just 2 1/2 years ago, and has been seizure-free ever since. I want to thank Liz Harris, who has been with us and who described what life has been like for her since she was 10 years old and had her first seizure, and how—although she has been able to manage and do very well, graduating from college and holding down a job—she knows that she is not seizure-free and she's hoping for the time when she, like Sharon, can be able to say that.

I want to thank Larry Gorski (phonetic), who came from the Mayor's Office on People with Disabilities, because it is very important that we recognize that it is not only the physical disability that we can see. And Larry pointed that out—he's in a wheelchair, but we can see that Larry is doing very well with his visible disability. But it's the invisible disabilities like those

brought on by epilepsy that we also need to be very aware of and very understanding of.

I also want to thank the Morrell family. Dr. Frank Morell's family joined me as we dedicated the epilepsy unit to Dr. Morrell. They certainly have a great deal to be proud of since Dr. Morrell pioneered the surgery that Sharon was able to have successfully. And then I met some patients who are ready for their surgery tomorrow and next week, thanks to Dr. Morrell's back-breaking work. I also want to thank Dianne McKeaver (phonetic) and others associated with the hospital and the board members of the entire staff for the work you do every day on behalf of all kinds of people and their problems.

I also want to acknowledge iVillage, which is one of our partners in creating a website about epilepsy that will bring much needed attention and encouragement, not only to those who are directly affected by epilepsy, but to countless others who care about this problem and what they all can do about it.

I was thinking about what the connection is between this event here in Chicago and probably the most important event that happened in our country today, and probably in the world—Michael Jordan's press conference and announcement of retirement. Literally, I understand that Michael Jordan's press conference was news that broke into whatever was going on throughout the world. You know, people sitting in (unintelligible) and Mongolia are watching TV, and all of a sudden they see Michael on the television. And it is certainly true that his retirement marks a sad day for all of us who are Bulls fans and Michael Jordan fans—and people who love basketball and sports around the world—because he brought to the game such skill that is indescribable and a competitive drive that was unmatched, as well as dedication and teamwork. And he really lifted us up as we watched him go whipping across that court, defying gravity and making it seem possible that, indeed, people could fly.

And the President and I both expressed a statement from the White House to give our personal best wishes to Michael and Juanita and their family. But as I read the comments that Michael made, because I was unable to watch the press conference as I was flying here, I was struck when he talked about the challenges he said still lay ahead for him. And he said that certainly one of the biggest challenges anyone can face is being a parent.

And that is true if our children are healthy. It is even truer if, like Susan or Lee Ann, we have a child with an acute or chronic condition that literally demands our attention, our concentration, our focus—as intense as anything like we'll ever do at our work—day in and day out to protect a Zachary from hurting himself, to make sure that a Laura doesn't lose her total self-confidence and feeling of herself as a human being as she suffers seizure after seizure.

And I also thought about all of the scientists like Dr. Morrell, and all the physicians here and elsewhere who bring that same commitment and teamwork to the work you're doing on behalf of epilepsy that Michael Jordan brought to basketball. I've often thought of him as not just an example for us who love sports, but as somebody who can tell us what it feels like to

reach really deep down inside and deal with any of life's challenges—many of which we don't know when they will come or where they will come from. But we can be certain that each of us will be challenged.

And today, you are helping to meet the challenges imposed by epilepsy. The progress we made here is a tribute to the tireless efforts we made here to the physicians, the nurses, the other staff members, and everyone associated with the work that has gone on here. I'm also very impressed that each of you understands so well that this is not just a medical condition—this is one that has social, economic, and psychological implications as well.

Those of you who work every day with people with epilepsy, and certainly those of you who either suffer from it or who have a family member who does, knows how widely it affects families and communities. And I don't think most Americans do. Part of the reason that I wanted to make epilepsy an issue that would be brought to wider public attention is that starting with the work that began on health care a couple of years ago, I have followed developments in health care the best a layperson can. And I've also followed the research that's being done to try to find cures, to push advances, to really cross new frontiers in medical science. And it struck me that, time and time again, we would make progress in a disease, and it would really feel very good in the investment that we made. But then I learned that when you take the number of people in our country who suffer from epilepsy—can you imagine with the amount of money that we have historically spent, that Congressman Davis referred to—that we have been spending far less trying to find the source, the reasons behind, and the cure for this condition than comparable diseases and other kinds of medical conditions.

As I got to thinking about that I realized that I, like many Americans, may have not paid sufficient attention to epilepsy and the costs that it extracts. Most people, for example, don't understand the terrible impact of epilepsy on children whose seizures produce developmental delays that can create a lifetime of dependence, loneliness, and unfulfilled dreams. Most people cannot see the heartbreak or hear the whispered prayers of parents who watch their children suffer. Most people don't know about the seemingly endless array of drugs, and hospital trips, and CAT scans, and blood tests, and treatments, and surgeries that patients with contractible epilepsy must endure.

And most people are not aware of the toll that this condition take on adults—on their ability to get or keep a job, drive a car, maintain relationships, or even have a positive self-image of themselves. I can only imagine how difficult it must be to live with those endless "what ifs": "What if I get a seizure when I'm crossing the street, or cooking for my family, or holding my baby in my arms?" Sharon told us about the seizure she had on a bus one time, not just once, but many times over and over again. While most people with epilepsy, thankfully today, can control their seizures, even they must live with something they cannot control—the cruel social stigma and stereotyping that comes with widespread ignorance of this disorder. That can damage the spirit as much as seizures themselves damage the brain. And clearly we have to do a better job of educating ourselves and increasing awareness among all Americans.

Today I am pleased to release a new study sponsored by the Epilepsy Foundation of America. This is a report to the nation aimed at heightening public awareness that this disease, this disorder, affects 2.3 million Americans, and it has a staggering cost to individuals and communities of at least \$2.5 million a year.

The report also makes clear that there will be approximately 181,000 new cases of seizures and epilepsy to occur this year—that's an annual figure—and that 10 percent of the American population will experience a seizure during their lifetimes. This is not a disease that leaves anyone out. It can strike at any age—from 6 months to 60, or 70, or 80 years of age—any person, any walk of life.

So we hope that this study will help to educate people about the effects of epilepsy and will help dispel misinformation and misunderstanding that are often as devastating as the condition itself. But we have to do more than public awareness, as important as that is. We have to do more research and we have to find a cure.

That's why I'm so proud of the unprecedented commitment that the President has made to fighting epilepsy and finding a cure. Under this Administration, funding for epilepsy research has grown dramatically—from a \$54 million commitment in 1995 to a projected \$76 million commitment this year.

Today, as a result of improved research and treatments, half a million Americans are receiving medical relief from their seizures and are able to lead normal, productive lives. Unfortunately, though, too many who suffer from epilepsy are still forced to choose from disabling seizures and debilitating side effects.

So while science has been able to solve many of the world's most common diseases in this century, the hundreds of thousands of Americans with intractable epilepsy suffer as much as those who had this condition hundreds, even thousands of years ago.

You know better than I the stories that come to this hospital, which has established itself as a world-wide center for the treatment and diagnosis of epilepsy. So with this audience of people who understand this condition, I'd like to list a few more things that I think we should be doing in order to help you do your work better, and to give more hope to people like Lee Ann and Susan.

We have to redouble our efforts to find a cure. Although we can celebrate the dramatic increase in federal funding for epilepsy research, we have to do more. I'm pleased to announce that next year, the National Institutes of Health will convene the first ever White House Initiated Conference on Epilepsy. More than 150 experts from around the country, and indeed the world, will participate, focusing on how best to allocate the unprecedented investment that has been made in epilepsy research.

Second, we have to do more to educate doctors about epilepsy. I heard from Dr. Smith how common it is for doctors who do not practice neurology or who do not see many epilepsy patients not to know what they are seeing, and therefore to misdiagnose the condition. When people with epilepsy are misdiagnosed, their condition continues to degenerate, often causing increasingly severe effects on brain development. So to address this problem, the Centers for Disease Control and the Agency for Health Care Policy Research are launching a new initiative that will reach out to thousands of doctors and inform them about how to make appropriate early diagnoses.

Third, we have to make information about epilepsy more accessible, in our schools, our doctor's offices, our communities.

So I'm also pleased to announce a new educational source. The Epilepsy Foundation of America and iVillage, an Internet company, will launch an Internet chat room that will offer consumers, patients and family members a safe and valuable opportunity to engage in live discussions with epilepsy specialists. It is very important that people who are searching for answers, and doctors, and others who are involved in this have a way of communicating and getting good and accurate information out to the public.

If we are going to see the end to the anguish and suffering of those with epilepsy, and find a cure, then all of us will have to do more to become involved—the government, the business sector, the not-for-profit sector, and certainly the medical and scientific research sector. Tonight, I will be attending a fund-raiser for CURE, a new advocacy group that has been founded here in Chicago to raise money for epilepsy research.

So, whether we're involved in raising private funds, or lobbying for more public support, or helping to educate our friends and neighbors, or helping to educate physicians—we can all do something to help bring the day closer when there is no more ignorance about epilepsy, and hopefully when there is no more suffering. What better way to carry on Dr. Morrell's legacy than to commit ourselves to fulfilling the vision of hope that he established here. And I would hope as well that those of you who are experts in epilepsy will find some time to reach into the larger community so that when a seizure occurs on a bus, or in an office, or in school, people will not back away or recoil in fear. But, instead, will understand that this is another condition medically caused and explained that we all have to do something about it. And that will give some comfort to those families that are struggling so terribly against the odds, to try to make sure that their children and their loved ones not only get the treatment they need, but that someday get the cure that they deserve.

Thank you all very much.