

International Institute For Human Empowerment, Inc.

Presentation to Saratoga Springs Lions on 9/30/10

Good afternoon, Fellow Lions. I am a Lion of 18 years, and proud to carry that honor. I work in the area of human rights and human empowerment, and I am proud to carry that label. I work in the area of parenting and grand-parenting, and I am especially proud of that designation. But I am also a concerned Lion, concerned human empowerment advocate, and concerned parent and grand-parent. I want to leave this world better than when I entered it. I am concerned that may not happen.

Lion Bill has asked me to talk in storytelling fashion, and I have for several weeks considered that request. I could talk about growing up in Appalachia with friends who never had the opportunities I had. I could talk about being the daughter of a U. S. District Judge who grew up from poverty during the depression, to become an attorney, to Prosecuting Attorney, Circuit Court Judge, and ultimately a Federal Judge.

I could talk about my wonderful Mother, a teacher certified in English, Math, and French who had students who loved her. I could talk about my Mother's struggles with what I now believe to have been Fibromyalgia, with no diagnosis or support.

I could talk about her 8 years with lung cancer, and her struggle in the face of 23 months on a feeding tube, 23 months minus three weeks in a hospital, and 18 months on a ventilator. I could tell you many stories about the struggles I faced in a culture within medicine that looked at her as having already had a good life--at the beginning of her struggle. I consider that ageism.

I could tell you all that I had to do to keep the physicians from following their general practice of discontinuing her life supports, even though her brain was fine. This was a medical practice that Dad and I vowed to fight, but he died 41 days after Mother, leaving only me to tell the story. The long hospitalization was because no nursing home in the State of West Virginia would accept a patient on a ventilator. While she had insurance, those without insurance were denied rehabilitation at the nearby Rehab. Hospital. This created a tragic situation for other patients.

I could tell you about growing up since age 10 with a wonderful relationship with Sen. Robert C. Byrd, from West Virginia, who passed away on June 28th this year. I used to tell him that he was like an Uncle to me, but when he passed,

Brian, my husband offered better insight. He was more like a second Father. I loved him passionately, and never once felt that it wasn't returned.

But I have other important matters to discuss today. I can tell you about the Institute that I started with a DBA in 1993, which became a not-for-profit corporation in 2000, and tax-exempt in 2002. We are registered as a public charity with the NYS Office of the Attorney General. That's all nice history, but it's not my real message.

I could also tell you that I became a Lion after serving food to the Lions in my Grandparents' restaurant as I was growing up. Much later, one day in 1988, without any preconception, I met Past International Director James Kent doing a white cane fundraiser in Price Chopper parking lot in Guilderland, NY.

I told Lion Jim that I wanted to know about Lions. He started to tell me, but I excitedly interrupted, and said that I knew about that. I wanted to become a Lion. I had never noticed there were no women, or at least hadn't paid any attention to that fact. After all, I was in public school administration at a time when I was the only woman in the executive meetings.

I learned that Lions Clubs International had recently begun taking women as members, and I became the first in that area. I wasn't doing it to break glass ceilings. I loved the mission of Lions.

So now, I want to tell you why I'm really here. About my concerns and passions. About what the International Institute for Human Empowerment is doing. And, if it resonates with you individually, or as an organization, how you can help.

I have left several publications for each of you to take. Our new brochure lists all of our activities. We have held an International Peace Meditation monthly for 14 years. Our meditations are posted on our website and e-mailed to about 1000 addresses. We do occasional Empowerment Retreats, and plan to increase this area in the future. We have a syllabus developed for teaching Empowerment in a college setting that we'll use when we find a college ready to embrace that area of study. Or, we may offer this course online and in-person through the Institute.

We publish electronically and in hard copy. You have examples to take with you today. Each area of publishing is a passion: from helping people improve their self confidence and the way they present themselves, to thoughts about social issues. We are hopeful that these thoughts will challenge thinking and

encourage debate. I once described my real mission as “planting seeds and making waves”. That’s what I believe good teachers do.

But now, for the real reason I’m here. Currently there are two major projects that the Institute is working on. They are quite different, at first glance, but they have areas of overlap. If you read our mission statement that we are dedicated to empowering all people toward a True Democracy through the attainment of basic human rights, including quality education, healthcare, food, and a peaceful, loving environment, you may see the fit. A True Democracy is defined as one “where all are equal, and all are truly free.”

Our first project focus is Fibromyalgia. Fibromyalgia is a multi-symptom, chronic pain syndrome of unknown cause. Pain can be accompanied by severe fatigue and sleep disorders, cognitive issues such as memory problems and mood disorders, TMJ, irritable bowel syndrome, carpal tunnel syndrome, allergies, underactive thyroid, Raynaud’s Phenomenon, multiple chemical sensitivities, muscle spasms, depression, restless legs syndrome, as well as increased sensitivity to temperature and weather changes, lights, sounds, smells, and even touch.

The pain of Fibromyalgia has been compared to the pain of Rheumatoid Arthritis, but unlike RA, does not cause joint deformity. One of the biggest challenges with Fibromyalgia is that there are no lab tests or X-Rays to confirm it. It is diagnosed by clinical history of pain in all four quadrants of the body for a period of three or more months, and evidence of pain at designated tender spots.

However, we do know that research has provided evidence of chronic pain, and lack of oxygen to some parts of the brain, by changes revealed on brain scans. We also know that patients have elevated levels of Substance P, a neurotransmitter. As a result, Fibromyalgia is now considered a neurological condition.

Fibromyalgia is occurring at alarming rates. Over two years ago, the National Fibromyalgia Association estimated that there are over 10 million people with Fibromyalgia in the U.S. That does not include all those undiagnosed, and worse, untreated.

Fibromyalgia is primarily diagnosed in women, but men and children have it as well. Unfortunately, it has not been taught very often in schools of medicine. Many, if not most, physicians, are not taught to diagnose it, and fewer know how to treat it. As a result, patients are falling through the cracks.

It is a sad commentary that it is the pharmaceutical companies that have done the most to raise awareness as they market the only three medications approved for treatment which are Lyrica, Cymbalta, and Savella. All of these medications were first developed for other conditions. None has been developed specifically for Fibromyalgia. All have side effects which, accompanied with increased sensitivities to medications that many Fibromyalgia patients experience, complicate treatment.

A typical patient takes 5 years and sees multiple physicians, to reach a diagnosis. This is a critical point. In that timeframe, jobs are lost and consequently insurance is lost, spouses and significant others leave, homes are lost, and people are forced to look to the government for support. One person who came to our support group had been considering suicide for the unrelenting pain and lack of understanding by her physician and spouse. It is especially sad that Dr. Kevorkian's last patient was a young woman with children who wanted to escape the pain of Fibromyalgia.

Fibromyalgia Patients are often viewed by their physicians as malingerers, only looking for a government handout, and their pain is left untreated. The situation is exacerbated by the fact that not only do few primary care physicians know how to treat this condition well, but sometimes specialists such as Rheumatologists, Neurologists, and Psychiatrists don't want to treat Fibromyalgia. (Incidentally, the American College of Rheumatology established the criteria for diagnosis in 1990). It has become a human rights issue as patients with this condition are being discriminated against in many instances because of physicians who are willing to diagnose Fibromyalgia, but refuse to treat it.

When I became a patient, I attended a Fibromyalgia Support Group at St. Peter's Hospital in Albany. It was a tremendous support. As my own situation began to stabilize, I continued to hear the stories from other patients about their situations of losing jobs, insurance, and their downward spirals. I decided I wanted to do something about it. In collaboration with the two support group leaders, and the wonderful physician Dr. Jonathan Cooper who had been the medical advisor to the support group for over 20 years, the Institute gave a free conference for patients and caregivers in Schenectady. As we are an all volunteer organization, all presenters donated their time. Price Chopper donated the room, and the Institute donated the organizing, legwork, and food. The following year, we gave a second free public conference on Fibromyalgia.

The third year of this work, we decided to hold a booth at the Women's Health Expo in the Concourse. It fell during the week of the National Fibromyal-

gia Association-sponsored National Fibromyalgia Day. The NYS Senate and Assembly sponsored Resolutions for Fibromyalgia Awareness Week in NYS. I was interviewed by Benita Zahn, and also recognized on the floor of the NYS Assembly for our work.

In the summer of 2009 we took yet another approach. Using a model that I had participated in when I was a public school administrator and also when I had worked at the NYS Education Department, I adapted a seminar model used by CASDA, the Capital Area School Development Association, which provides staff development to over 100 school districts in the Greater Capital Region.

The seminar model, developed by Dr. Nelson Armlin, had been used for action research in education for over 30 years, using teachers and administrators at all levels within public and private schools. I expanded that model for this project, to include a much broader community: a Neurologist specializing in pain management at Albany Med, two medical researchers at Albany Med, a Physiatrist, a former BOCES District Superintendent, public school administrators, a legislative analyst, business, patient advocate, Social Security Disability Attorney, Human Rights Disability Attorney, Fibromyalgia patients, massage therapists, and an Occupational Therapist. These 21 people met for four days in the summer of 2009. The result of that Select Empowerment Seminar is the document, Fibromyalgia: Awareness, Advocacy, and Action. You can see on page 13 that this year the work of the Institute was recognized in the Senate Resolution for Fibromyalgia Awareness Week in New York State. We were recognized by Sen. Betty Little on the floor of the NYS Senate. Fibromyalgia has received much support from Sen. Betty Little and Assemblywoman Audrey Phefer and many others.

Using an unrestricted grant for \$10,000 from Pfizer to support our mission, we held our four seminar days, and published 2000 copies of our Fibromyalgia Report which were distributed to hospitals locally, and in Virginia, West Virginia, and Florida. They were sent to an interested physician in Indonesia. They were distributed in the Capital Region to places of business, physicians' offices, massage therapy offices, patients, at health fairs such as last years Saratoga Lions health fair, Best Fitness gym, etc.

In Saratoga, Dr. Karen Schick was given 100 copies to share with physicians and patients. Dr. Robert Carpenter, took copies for his waiting room. The copies disappeared quickly.

With money we received from sponsoring a carnival, we printed another 3000 copies. We also made it available on the Institute website for a free download. We feel this Report is written not just for physicians and patients, but all who want to help. Chronic pain and other symptoms are forcing more and more people to have leave work and to accept Social Security Disability. I didn't want to; I had to. This is how I give back.

Fibromyalgia is putting a strain on our social systems, and patients are being victimized. It's still hard for me to believe this, but I heard one Psychiatrist (doctor of rehabilitation medicine) say, "Why should I take Fibromyalgia patients when I can inject Cerebral Palsy patients with Botox?" Fibromyalgia patients don't usually require the treatments that provide financial incentives for physicians.

Our second project, in which you might also want to become involved, is 'International Unity Day' and related efforts to enhance understanding and relationships across boundaries of race, gender, disability, age, lifestyle preference, social class, and all other boundaries. These characteristics too often tend to separate us within the human family. While I have been writing about diversity for several years, the 10th anniversary of the Institute this year, as well as the 10 anniversary of International Unity Day, called for something more.

This year, as a few of you know, we held an event in Latham on September 9th. In preparation for that event, I compiled all that I had ever written on Diversity, including some new material and also unpublished material, into a new book called Celebrate Diversity!. I won't take your time with details here, but this book has sections that can be used in our community organizations, our schools, and also in corporations and government.

The final section of essays is to broaden the thinking of each individual as we all need more perspective and information about a topic than we actually use, when we teach or provide professional development. We need to see the big picture. We need to be firmly grounded, and modeling that which we teach others.

In a culture full of silent messages about who we should, and sometimes shouldn't, interact with, it broadens our perspective to see the wonderful diversity of the human race as an asset, rather than a detriment. This book gives us some leadership for doing that.

I have five grandchildren: Myles, Elaina, Elijah, Christian, and Ava. What will their world be like? What will the world be like for your children and grandchildren, and theirs? Will we continue to fight religious wars, class wars, wars

over resources, and continue to respond with endless revenge? 'We cannot destroy violence. We can only create peace.' How we think, act, and what we each model for our younger people, will determine their destiny.

We have made strides, but I believe that we are right now in deep jeopardy. The events of 9/11 changed our world. We're more suspicious. We have more focus on fear and subsequent security needs. Yes, we have to protect ourselves or foolishly succumb. But, we also need, for the sake of our children, to replace images of buildings falling, people running in fear, and the stories of horrible loss that we will forever feel. We need to replace those images with images and celebrations of what can and must be, for them.

Each year on September 11th, we commemorate those who were lost, and all those who will forever mourn, while honoring them by establishing a permanent memorial to hope and peace in our hearts. We call that permanent and positive memorial, 'International Unity Day'. You can read about 'International Unity Day', suggested activities, sample proclamations and possible news releases in Celebrate Diversity! or on our website at humanempowerment.org and selecting the globe.

Stop our enemies? Yes! Teach hate and fear? No. There is no 'peace at any price'. But there also is no peace without living and teaching caring and empathy. That's also why I'm a Lion, and so are you.

The International Institute For Human Empowerment has no paid membership. Its membership is by philosophy alone. We are more than an organization. We are a Human Empowerment movement. Our website is visited regularly by over 100 countries. While we might anticipate countries such as Australia, Canada, and Europe, our most recent visitors to our website are Botswana, Bangladesh, and Estonia. For the past several months, the Russian Federation has been our most frequent foreign visitor. "Our message is global; our efforts are local." We are not affiliated with any religion in order to be able to serve all people.

How can you help? Visit our website. Join our mailing list. Forward our e-mail to your friends and colleagues. Hand out our publications to anyone interested. Contribute to our printing and mailing. We are in a fundraising mode as I loaned \$9,000 recently to the Institute for printing and other costs. That investment allowed us to publish. Now we need to look to others for support. You can help us by linking us with those who can help us--businesses and people, who will support this mission.

Another way you can be involved is to proclaim 'International Unity Day', and to start an annual celebration the week of September 11 by Saratoga Lions and other businesses in town. You can see information on how to do that in the community section of [Celebrate Diversity!](#)

Currently the Institute is working with Albany Medical Center on a new project about Fibromyalgia. We are helping Albany Med. Neurosciences by informing Fibromyalgia patients and others about their new clinical trials using Cymbalta and Savella, Fibromyalgia medications. We are also discussing with the Neuroscience Department developing continuing education credits for physicians about Fibromyalgia.

We collaborate with the New York State Division of Human Rights on both of these projects. They share their professionals in our projects, and we donate books to them to use as a basis for awareness and training.

We also collaborate with many others and this will continue to expand. We donate to LCIF (The Institute donated \$1000 for the Asian Tsunami), and local Lions projects. For example, the Institute was a sponsor for the Duathlon, the Golf Tournament, and our Lions Health Fair. On September 9, at our Latham event, the Institute donated \$500 to the Lions Eye Institute to become a Knight of the Blind.

When I was Lions Region Chair, we did a collaborative project with the Lions Eye Institute, Lions Clubs in the Region, and our Institute. Together we raised \$1650 for an interpreter for a school sponsored trip for a student who was both blind and deaf. That's how Lion John McDonald and I first worked together. Recently I joined the Board of the Lions Eye Institute.

We've donated to Gilda's Club, Dudley Observatory, Thomas Patrick Morrison Foundation for children with rare diseases, Barton Camp for children with Diabetes, and many more. We were recently described as running the Institute on a shoestring. It's true. I prefer to think that we do what is put before us to do, and the money follows. Dad called that being in the flow.

Thank you for listening, for being caring and wonderful contributors to the community, and for caring about those whom you will never know or see. It matters. You matter. You make me proud to be a Lion.

Sue Kidd Shipe, Ph.D., Executive Director

This is the complete presentation which was delivered with some omissions due to time constraints.