Sick and Tired of Feeling Sick and Tired

Living with Invisible Chronic Illness

by Paul J. Donoghue, PhD and Mary E. Siegel, PhD


Introduction to Invisible Chronic Illness

“I want to be well. I’m willing to fight, but…”

“But what?” Dr. Diamond asked. “But I must know what I’m fighting. I must have a name for this illness of mine.” – Henrietta Aladjem

Recently, returning to Stamford, Connecticut, from a talk in New York, we turned off the highway behind a young man on a motorcycle. As we entered an intersection on a local street, the cyclist suddenly skidded and, in attempting to right his vehicle, spun out of control. We pulled over immediately and rushed to his still form. Within seconds, we were joined by other motorists who had pulled to the side. Some of us held his hands and murmured soothing words, others gathered his wallet, keys, and coins and carefully placed them in a pile next to him. Another person ran to a phone booth at a nearby gas station to call the police. In the space of a few minutes, all our efforts were employed unquestioningly to care for this young man. Later, we reflected on the fact that, faced with such evident disaster, we all responded, as if by instinct, to the needs of the young motorcyclist. Our own needs to get home to rest after a long day or to reach an appointment on time were temporarily suspended in favor of our concern for the cyclist.

The human potential to reach out in care seems to be tapped particularly when the need of the other is indisputably apparent. National disasters, such as the earthquake in Armenia in 1989, inspired an international outpouring of aid in the form of technological and medical assistance, despite the more typically felt restrictions of ideological differences between nations. The deep, instinctual, human capacity to act compassionately when confronted with disaster can overcome the powerful pull of skepticism, anger, or hate.
What happens to this human reaction when the crisis of the person is not as patently clear as we witnessed in the fallen motorcyclist? When, for example, a man stumbles in front of us, we may start to wonder, “Is the person about to fall? Has he drunk too much? Is this just a momentary loss of balance?” Once we start to puzzle over the reason, we hesitate. “Does this person need my help? Did he do something that he shouldn’t have that caused his stumble? Is he fine?” Unsure as to the cause of the stumble, we are less likely to move swiftly into action than if the person did, for instance, actually faint. And if we suspect that he has brought his problem on himself by doing something fool-hardy or inappropriate, we may become judgmental and refuse to provide help even if requested. In our hesitation, we may begin to feel self-protective, “Will I be rejected if I offer help? Will I risk being hurt physically? What if the person resents my offer of help and regards it as an insult?” Such reflection diminishes the immediate impulse to provide care for the other.

The dilemma described above is at the heart of the distress felt by millions of people who suffer from invisible chronic illnesses (ICI), that is, diseases that are characterized by chronicity and symptoms that are not externally manifested. Symptoms common to invisible illnesses are chronic fatigue, chronic pain, memory loss, transient vision disturbances, muscle weakness, bladder urgency, peculiar physical sensations (numbness, tingling, “pins and needles,” hot flashes), skin irritation, intestinal distress, and cognitive difficulty. These symptoms do not show up in a way that makes it obvious to an observer that a person is suffering. Unlike a wound that bleeds or requires stitches, a mending limb that is encased in a cast, or malfunctioning legs that necessitate use of a wheelchair, the symptoms of invisible illnesses have no external evidence of suffering that elicit compassion. Instead, the patient often endures suspicion and withdrawal from others. And so, in addition to disturbing, even agonizing and disabling symptoms, the patient of invisible illness suffers, often deeply, from the negative reactions of others. Such reactions frequently lead the patient to confusion, loneliness, self-pity, and self-doubt.

A patient, Anna, who is suffering from fibromyalgia, a condition that cases chronic pain, related this incident to us:

I was standing on line at the passport agency. The room was very warm and the wait seemed interminable. I thought at one point that we had been standing for fifteen minutes without any turnover at the counter. The pain traveling across my shoulder and down my right arm was excruciating. Childishly, I wanted to lean head on the man in front of me. I wanted to cry or throw a tantrum and toss my papers on the floor. I considered approaching the agents to tell them that I needed special assistance. But I felt reluctant, wondering what I would tell them. If I said, “I’m in pain so hurry me through,” you can imagine the look I would get. I even fantasized about going up and saying, “I have cancer and I’m dying. Can you speed up the process?”

In the middle of these thoughts, a man in a wheelchair entered the stuffy room looking lost. A passport agent went to his side and bent towards him.

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With the launch of the SSF 5-Year Breakthrough Goal, 50in5: “To shorten the time to diagnose Sjögren’s by 50% in 5 years” we are also hoping to change how Sjögren’s is understood.

The Foundation knows how isolating being diagnosed with an invisible illness can be, but you are not alone. There are an estimated 4 million Americans suffering from Sjögren’s, both men and women of different ages and ethnicities.

This is why we are launching a new awareness campaign for our website, www.sjogrens.org, called “Faces of Sjögren’s” where we want to share your stories!

As a way to help recently diagnosed patients, in addition to helping others find a diagnosis quicker, these stories will help others relate because no patient is alone. Whether you are a patient, doctor, loved one or family member, we want to know your own personal experience with Sjögren’s. With your help, we hope this project will help us reach our 5-Year Breakthrough Goal!

When submitting your story:

- Stay within 250 words
- Include aspects of how Sjögren’s has affected your life and ways you have been able to effectively cope with your symptoms
- Include a few personal words of inspiration
- At the beginning of your story, please complete the following phrase, “When I was diagnosed with Sjögren’s, my first thought was…”
- And don’t forget to include a picture of yourself!

Email your story to tms@sjogrens.org with the subject “Faces of Sjögren’s” or mail them to the SSF office. Together we will conquer Sjögren’s!
They spoke for a few minutes. Then she brought him forms and completed them for him. She gathered their completed work up in her hands and took them with her and disappeared behind the counter. She returned shortly with papers in hand. They exchanged a few words again, he signed the papers, and then turned his wheelchair towards the exit, which the agent opened, and left.

I felt tears of frustration spill down my face. I had been standing in utter pain for thirty minutes and contemplated a possible twenty more. For the millionth time since I have had to deal with this condition, I “wished” that I bore some sign that revealed the suffering I am enduring and then maybe others would assist me as the passport agent had helped the man in the wheelchair.

Then I felt small and selfish for having those thoughts. God knows, I don’t want to be disfigured or incapable of walking. And believe me, I didn’t begrudge for a second the help that the man in the wheelchair had received. I was even impressed by and admiring of the agent who had, of her own accord, gone out of her way to make obtaining a passport as easy as possible for him. But, oh, how I resented this disease that makes me suffer so terribly and restricts my life, at the same time that no one can see the suffering and no one offers help.

Anna’s experience at the passport agency typifies the stressful consequences of chronic invisible illnesses. Diseases such as chronic fatigue syndrome, irritable bowel syndrome, HIV infection, multiple sclerosis (MS), endometriosis, Crohn’s disease, fibromyalgia, and lupus erythematosus, though vastly differently illnesses, share characteristics that encompass invisible illness. They are diseases that cause extraordinary pain, fatigue, and a multiplicity of other symptoms that result in great distress and disability. These symptoms may seem to be the kind that most of us feel from time to time. Pain, for example, is part of everyone’s life. We feel it with a minor sunburn, a stubbed toe, a bruise, or a hangnail. We feel it more intensely from a broken limb, from a third degree burn, or after surgery. It is part of an inborn warning system that notifies us that something needs to be tended to, whether with rest, medication, or a band-aid. For the most part, when the cause of pain is removed or when a recuperative period is over, the pain lessens and eventually retreats completely.

For chronic pain sufferers, however, there is rarely sufficient relief from pain and always the threat of a lifetime of pain—pain more intense than any caused by the bumps and bruises of a normal life. It may be as intense as that which is experienced after surgery but without any promise of relief. The quality of this pain is so different from transient aches and pains that language is inadequate to the task of describing it.

Similarly, fatigue is a symptom of some of these illnesses. At some point in the day, we all feel tired. We feel tired when we work too hard, don’t sleep at night, or exercise too vigorously. There are myriad reasons for feeling tired. Like pain, tiredness is ordinarily the body’s means of telling us that it is time to rest. Fatigue for those with chronic illnesses, however, can actually be disabling. This fatigue is relentless. Overexercise or overwork does not cause it and bed rest frequently fails to relieve it. It appears regardless of activity or inactivity, happiness or sadness. It simply exists in and of itself, and no medication, positive thought, or rest can relieve it.

Nonmeasureable Symptoms

Symptoms of invisible chronic illnesses are not only non-observable, but also typically immeasurable. They are subjective experiences. Thus, if a person who is suffering from multiple sclerosis notes that his memory seems to be lacking, there are few measures to determine whether indeed his ability to remember is failing. If someone cannot remember his name, family, or occupation, we acknowledge a serious and evident condition of amnesia. But when the memory loss is subtle and transient, we must rely on the person’s self-awareness and description of the impairment. The person’s subjective experience, however, is one that the patient, his family, and health-care providers reluctantly trust. The patent may wonder, “Is this really happening or am I just tired?” The patient’s wife may reflect, “He always forgets at the most inopportune times, like when he is supposed to pick up a few groceries.” The doctor may muse, “This patient is under too much stress.” Without proof of a deficiency, such as results of medical tests, everyone seems bent on disproving the possibility that there has indeed been memory loss—the patient because he is self-doubting, the family members because they are suspicious, frustrated, or frightened, and the doctor because he doesn’t observe any perceptible problem.

James, who has “mild” multiple sclerosis, describes a typical experience of what it is like to have a problem that is experienced but cannot be proven:

I have been playing golf for fifteen years, and every Saturday in the past few years I have played with three buddies of mine. We wager on each hole. Lately, when we finish a hole and I try to count my strokes, I can’t remember a thing. It’s weird. No matter what I do, I just can’t remember the strokes. At first, we all laughed—joked about getting older. But after a while my partner
Ask your physician to prescribe Numoisyn today!

Numoisyn Liquid

Prescribing Information
Ingredients: Water, sorbitol, linseed (flaxseed) extract, Chondrus crispus, methylparaben, sodium benzoate, potassium sorbate, dipotassium phosphate, propylparaben.

How Supplied: 30 mL per bottle or 300 mL per bottle.

Therapeutic Group: Numoisyn Liquid is an oral solution formulated for the relief of chronic and temporary xerostomia (dry mouth), which may be a result of disease, medication, oncology therapy, stress, or aging.

Indications: Numoisyn Liquid is indicated for the treatment of symptoms of dry mouth. Numoisyn Liquid relieves the symptoms of dry mouth by enhancing swallowing, improving speech mechanics, and lubricating the oral cavity like natural saliva. Numoisyn Liquid may be used to replace natural saliva when salivary glands are damaged or not functioning. The viscosity is similar to that of natural saliva.

Contraindications: Numoisyn Liquid are contraindicated in patients with a known history of hypersensitivity to any of the ingredients.

Special Precautions for Use: As Numoisyn Liquid contains linseed (flaxseed) extract, patients with irritable bowel syndrome or diverticular disease or those on a high linseed diet may experience abdominal discomfort.

Warning: Federal law restricts Numoisyn Liquid to sale by, or on the order of, a physician or properly licensed practitioner.

Interactions: There are no known interactions between Numoisyn Liquid and any medicinal or other products.

Directions for Use: Shake bottle well. Take 2 mL (about 1/2 teaspoon) of Numoisyn Liquid and rinse around in the mouth before swallowing. Use as needed.

Side Effects: Patients may experience difficulty in swallowing, altered speech, and changes in taste. If side effects persist or become severe, patients should contact a physician.

Storage: Store at room temperature. Do not refrigerate. Use within 3 months of first opening.

KEEPS OUT OF REACH OF CHILDREN.

Please Note: Numoisyn Liquid is translucent and may contain some natural particles that do not affect the quality of the product.

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Godalming, Surrey GU7 1XW UK
Distributed by ALIGN Pharmaceuticals, LLC
Berkeley Heights, NJ 07922 USA
www.alignpharma.com

Numoisyn Lozenges

Prescribing Information
Ingredients: Sorbitol (0.3 g per lozenge), polyethylene glycol, malic acid, sodium citrate, calcium phosphate dibasic, hydrogenated cottonseed oil, citric acid, magnesium stearate, and silicon dioxide.

Pharmaceutical Form: Oral lozenge

Contents: 100 lozenges per bottle. Net weight of 40 g (0.4 g per lozenge).

Therapeutic Group: Numoisyn Lozenges are oral lozenges formulated to promote lubrication of oral mucosa that may be dry due to a variety of circumstances, including medication, chemotherapy or radiotherapy, Sjogren’s syndrome, or oral inflammation.

Indications: Numoisyn Lozenges are indicated for the treatment of xerostomia (dry mouth). Numoisyn Lozenges provide temporary relief of dry mouth due to damaged salivary function. Numoisyn Lozenges are formulated to support the natural protection of teeth provided by saliva so that no damage occurs to teeth with repeated use of the lozenges.

Contraindications: Numoisyn Lozenges are contraindicated in patients with fructose intolerance or a known history of hypersensitivity to any of the ingredients.

Warning: Federal law restricts Numoisyn Lozenges to sale by, or on the order of, a physician or properly licensed practitioner.

Interactions: There are no known interactions between Numoisyn Lozenges and any medicinal or other products.

Directions for Use: Let one Numoisyn Lozenge dissolve slowly in the mouth when needed. To obtain optimal effect, move the lozenge around in the mouth. Repeat as necessary. Do not exceed 16 lozenges in 24 hours.

Side Effects: Excessive consumption can cause minor digestive problems.

Storage: Store at room temperature. KEEP OUT OF REACH OF CHILDREN.

Overdose: No overdoses have been reported to date.

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was getting pissed off. My forgetting was interfering with our game. Once we gave up a hole because I just couldn’t be sure about a stroke. We’ve figured out a way to keep count, but it’s embarrassing and it isn’t funny anymore. It is strangely happening at other times too. Like I’ll watch a news program and my wife will ask about a news item that I’ve just seem and I’ll be completely blank. I can’t remember a sequence of information. I can remember the last part—strange.

I have this sickening sensation in my stomach as I strain to remember. I try to remember rather than just admit to myself that I can’t and then relax.

I was so disturbed that I went to the neurologist. He asked me to describe my memory problems and when I was finished he chuckled a bit and said, “You know, Jim, we are all getting older—you probably have to start keeping lists.” When I told him that I had done some reading about multiple sclerosis and memory loss as a common symptom, he said “So they say, so they say. But I don’t think so. The researchers keep debating the issue. You just have to make sure that you are getting enough rest. Who knows, it may be that your limp so distracts you when you are playing that you lose some of your concentration.” I felt foolish when I felt the office. I felt like I would have to argue with him to get him to understand that I really had a problem. But I figured it wasn’t worth the bother since there wasn’t anything he could do for me anyway.

But I would have liked to have been able to tell my wife, “The neurologist confirmed that something is wrong with my memory.” She wants to understand, but she thinks I’ve always been absentminded and now I’m even more so. I’m not sure why I need anyone else to acknowledge what is happening to me. I feel furious when it happens. I guess I want to prove that it’s really happening.

**Diagnostic Dilemma**

Jim’s frustration with the immeasurability of his memory loss illustrates another integral aspect of the phenomenon of chronic invisible illnesses. Invisible diseases are so difficult to diagnose that they tend to be identified by the process of eliminating other disease possibilities. Patients become aware of vague, sometimes transient symptoms. Multiple sclerosis, for example, may appear initially as numbness in the limbs. The patient may dismiss the symptom as a result of excessive exercise; when he changes his exercise routine and the numbness passes, he is convinced that the new regimen relieved the problem. Then a new symptom occurs, such as intense fatigue, and the patient may feel compelled to see a physician.

Once the patient visits the physician, both he and the physician are confronted with the task of identifying the underlying cause of the symptom. Identifying the source is complicated by the type of symptoms that are described—numbness, fatigue, vision disturbance, pain. These symptoms defy medical measurement. They appear to be vague and unrelated. A persistent patient and a responsible doctor face the challenging prospect of determining the causes of the symptoms through the process of eliminating one possibility after another. The process is anxiety-provoking, uncomfortable, time-consuming, and costly. Doctor and patient struggle with the suspicion that the symptoms are psychosomatic or

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that the patient suffers from a mental disturbance. With each visit to the doctor and each test, the patient becomes hopeful that, at last, he will have an answer. Fear and dread of having a serious illness are surpassed by the driving need to know “What is making me so miserable?” This need to know is associated with the belief that “Once I know what I have, then I can handle it and receive treatment that will make me feel better, and I’ll know that I’m not crazy.”

Unfortunately, for patients with ICI, the diagnosis brings short-lived relief. The fear that the disease will attack vital organs, as, for example, in lupus or multiple sclerosis, replaces the relief felt on hearing the diagnosis. The diagnosis of post-polio syndrome triggers terrifying reminders of illness. For patients who are diagnosed with chronic fatigue syndrome, irritable bowel syndrome, or fibromyalgia, there is the disturbing fear that the disease has not been accurately identified. One patient cried, “How can I feel this awful and have something as vague and untreatable as irritable bowel syndrome? I am so afraid that someday they’ll find that I have cancer, but then it will be too late.”

Ellen’s experience is typical of a diagnosis built upon a bewildering process of elimination:

A year and a half ago, I started feeling this pain in my hand and somewhat in my shoulder and arm. I was pretty sure that the pain was caused by this new weight-lifting program I was doing. So I stopped for a while, but it got worse anyway. They thought at first that I had something called carpal tunnel syndrome. One doctor wanted to operate right away, but another advised me to wait. Now they are sure that it isn’t carpal tunnel, but they aren’t sure what it is. This last year the pain has gotten worse all the time. It is mostly in my neck, shoulder, and left arm. It had gotten so bad that I had to quit my job. I can’t concentrate or complete anything. Sometimes I wish I could just die, I am so overwhelmed with the pain.

I think I’ve had every test you can think of: MRI, EKG, EEG, spinal tap, X-rays, blood test, and urine tests. I’ve tried so many medications that my bathroom shelves look like a pharmacy. I decided to stop taking some narcotic pain relievers because I was afraid of the side effects, but I went through horrible withdrawal that was almost as bad as the pain. I’ve tried physical therapy, hypnotherapy, homeopathy, and biofeedback. They helped a little. Some of the medications helped somewhat too. But I’m still in pain.

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And—this is what is so unbelievable to me—I still don’t know what I have. They have kind of reached a consensus that it is fibromyalgia, but one doctor said he doesn’t even believe that there is such a condition. He said it is just a “catch-all” term that is used when there is no other explanation.

When Ellen first told us her “story,” she felt sure that her experience was unique. She was startled but comforted by the realization that she was not alone in her quest to find a name for her illness and a means of coping with it. For those of you reading this book who recognize the experience of illness that we have described, we hope that the following chapters comfort you and inspire you to love with your illness in a way that gives you dignity, confidence, and hope.
For patients with Sjögren’s syndrome

DRY-MOUTH SYMPTOMS DON’T HAVE TO BE SO DISTRACTING.

If you experience dry-mouth symptoms due to Sjögren’s syndrome, then you already know how distracting these can be to your daily life. It might be time to ask about EVOXAC® (cevimeline HCl), a prescription treatment that works by stimulating the production of your body’s own natural saliva.

Talk to your doctor to see if EVOXAC can help, or visit DiscoverEVOXAC.com.

Please see important information about EVOXAC below.

Important Safety Information

What is EVOXAC?
• EVOXAC (cevimeline HCl) is a prescription medicine used to treat symptoms of dry mouth in patients with Sjögren’s syndrome.

Who Should Not Take EVOXAC?
• You should not take EVOXAC if you have uncontrolled asthma, allergies to EVOXAC or a condition affecting the contraction of your pupil such as narrow-angle (angle-closure) glaucoma or inflammation of the iris.

What should I tell my Healthcare Provider?
• Tell your healthcare provider if you have any of the following conditions:
  • History of heart disease;
  • Controlled asthma;
  • Chronic bronchitis;
  • Chronic obstructive pulmonary disease (COPD);
  • History of kidney stones;
  • History of gallbladder stones
• Tell your healthcare provider if you are trying to become pregnant, are already pregnant, or are breastfeeding.
• Tell your healthcare provider about all medications that you are taking, including those you take without a prescription. It is particularly important to tell your healthcare provider if you are taking any heart medications especially “beta-blockers”.
• If you are older than 65, your healthcare provider may want to monitor you more closely.

General Precautions with EVOXAC
• When taking EVOXAC use caution when driving at night or performing other hazardous activities in reduced lighting because EVOXAC may cause blurred vision or changes in depth perception.
• If you sweat excessively while taking EVOXAC drink extra water and tell your health care provider, as dehydration may develop.
• The safety and effectiveness of EVOXAC in patients under 18 years of age have not been established.

What are some possible side effects of EVOXAC?
• In clinical trials, the most commonly reported side effects were excessive sweating, headache, nausea, sinus infection, upper respiratory infections, runny nose, and diarrhea.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.FDA.gov/medwatch, or call 1-800-FDA-1088.
Please visit www.EVOXAC.com for full Product Information for EVOXAC.

For patients having difficulty affording their Daiichi Sankyo medication, please call the Daiichi Sankyo Patient Assistance Program at 1-866-268-7327 for more information or visit www.dsi.com/news/patientassistance.html.

Please see a brief summary of Important Information for EVOXAC on the next page.
## EVOXAC® Capsules (clemastine hydrochloride)

### INDICATIONS AND USAGE

Clemastine is indicated for the treatment of symptoms of atopy in patients with Sjogren's Syndrome.

### CONTRAINDICATIONS

Clemastine is contraindicated in patients with concomitant asthma, known hypersensitivity to clemastine, and when aerosols are used, e.g., in acute flares and in non-steroidal inflammatory drugs (NSAIDs).

### WARNINGS

Cardiovascular Disease:
- Clemastine can potentially exacerbate existing cardiovascular disease or lead to cardiovascular disease in patients with a history of cardiovascular disease. Therefore, clemastine should be administered with caution to patients with known cardiovascular disease.

Pulmonary Disease:
- Clemastine can potentially increase airway resistance. Acute respiratory distress, bronchial asthma, and bronchospastic conditions.

### PRECAUTIONS

General:
- Clemastine is contraindicated in patients with known hypersensitivity to clemastine.

### ADVERSE EFFECTS

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* * is the total number of patients exposed to the dose at any time during the study.

### MANAGEMENT OF OVERDOSE

Management of the ingestion and symptoms of acute overdose should be handled in a manner consistent with that indicated for other antihistamines. General supportive measures should be instituted if medically indicated, dyspnea, as an antihistaminic agent, may be of value in the treatment of acute overdose in patients who are unresponsive to standard supportive measures. If medically indicated, epinephrine may also be of value in the presence of severe cardiovascular depression or bradycardia/ventricular dysfunction. It is not advisable to administer epinephrine. For further information, consult a physician.

### ADVERSE EVENTS

No adverse events were reported in Sjogren’s patients. For further information, consult a physician.

### DOSAGE AND ADMINISTRATION

Clemastine should be administered as instructed by the physician. In general, the recommended dosage is 30 mg once daily for adults and children over 12 years of age. The dosage may be increased to 60 mg if necessary.

**References:**
- [Deyo RA](https://www.ncbi.nlm.nih.gov/pubmed/25833333)
- [Forbes A](https://www.ncbi.nlm.nih.gov/pubmed/25833333)
- [Sharma N](https://www.ncbi.nlm.nih.gov/pubmed/25833333)
- [Smith J](https://www.ncbi.nlm.nih.gov/pubmed/25833333)
- [Jones K](https://www.ncbi.nlm.nih.gov/pubmed/25833333)
- [Deyo RA](https://www.ncbi.nlm.nih.gov/pubmed/25833333)

**For additional information please call 1-877-437-7763**

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It is with a heavy heart that the SSF announces that our friend and SSF Director of Field Services Cynthia Williamson passed away in a car accident on Saturday, August 18th at the young age of 27.

Cynthia’s energy, dedication and persistence was the perfect example of a person who “stood up” for Sjögren’s. Just look at her picture at the Nashville Marathon as she cheered on our Team Sjögren’s runners! Cynthia always went the extra mile to ensure that our volunteers, donors and Sjögren’s patients always knew how important they were to the SSF. She truly always stood up!

Cynthia joined the SSF in January 2008 and made incredible contributions during her tenure with the Foundation. Last year, Cynthia was promoted to Director of Field Services due to her commitment and leadership qualities. For those who worked with Cynthia, you quickly saw her dedication in helping Sjögren’s patients through her work with our 65 support groups, our Team Sjögren’s Marathon Training Program, our National Patient Conferences, our Sjögren’s Walkabouts as well as many other initiatives and events.

Cynthia will be missed by her friends and co-workers here at the SSF as well as by her family including her three beautiful children, her mother and step-father, and her dedicated and loving siblings.

As a way to remember Cynthia, we hope you will all take the time to hug your children and grandchildren – as Cynthia loved kids. Cynthia also believed that the SSF was her extended family and she was always working towards increasing awareness for Sjögren’s patients. So in her honor, we hope you will step up and do something to change the face of Sjögren’s! We know she would love to know that she inspired one person to go out and make a difference.

We will miss Cynthia, but together we can ensure her legacy continues on!
Our Friends raised an outstanding $17,825 for this year’s campaign!

The following three names were drawn as the winners of the Friends Helping Friends Campaign:

Barbara of Chicago, IL  Colleen of Ridgefield, WA  Geraldine of Madison, CT

The winners have been awarded a Lifetime Membership to the Sjögren’s Syndrome Foundation.

Congratulations! and Thank You for participating in the 2012 Friends Helping Friends Campaign!

IT’S TIME

United Way • Combined Federal Campaign • State Payroll Deduction

Each fall your local United Way, Combined Federal Campaign, state employee, and private employer payroll deduction campaigns begin. We hope you will remember the Sjögren’s Syndrome Foundation when choosing where to allocate your donation.

If we are not listed on the contribution form, you usually may write in the Sjögren’s Syndrome Foundation.

Tell your co-workers, friends, and family members how important it is to choose and write in the Sjögren’s Syndrome Foundation on their campaign form, too.

If your employers will not allow you to write in the Sjögren’s Syndrome Foundation, remind them that we are a national non-profit 501(C3) organization and qualify for most payroll deduction campaigns. If they need more information, please contact the Foundation at 800-475-6473 ext. 207 and ask for Ben Basloe.

Just think – every dollar counts.

Last year alone – thanks to those who chose to give through their employer’s payroll campaign – the Sjögren’s Syndrome Foundation was able to increase its Research and Awareness commitments.

Remember, the Foundation has received the:

- Best of America
- National Health Council Standards of Excellence
In Memory of Barbara Hardin
Yolanda & Sara

In Memory of Betty Strock
Linda & Larry Levin
Judy & Bernie Galtman

In Memory of Cecilia Hauck
Roger, Adeline & Teresa Rzonca
Sally Fernholz
Patricia & John Radabaugh

In Memory of Charlene Prybylski
Pat Sand

In Memory of Dean Soliday
State of Connecticut Dept. of Transportation

In Memory of Debbie McGovney
Kim McHale

In Memory of Eileen Hardesty
Joan Hardesty

In Memory of Elaine Dillberger
Ann Elizabeth Johnson
Lois Kiefer
Friends at Dell EqualLogic
Pauline Curtis
Phyllis Powder
Robert & Sharon Blackwell
Elaine & Charles Clark
Claire & Greg Smith & Family
Hampstead Circle of Lutheran Church of Reconciliation
Shirley Galisdorfer

In Memory of Elizabeth Fields
Kathleen Williams

In Memory of Eleanor Jarrells
Susan Lindberg
Peggy Hedback
Karen & Mark Larson
Steven & Susan Carlson
Eris & Steven Cole-Hunter
Mary & Dale DeVries

In Memory of Elliot Weisenberg
Elaine & Larry Levin

In Memory of Hope Gonzalez
The Castagno Family

In Memory of Jane Coffey
Maurice & Edith Eash

In Memory of Janice Polisner
Barbara & Steve Waxter

In Memory of Jay Feiner
Elaine & Larry Levin

In Memory of Jean Basso
Linda Danek
Judith Batteen
Sally Beaudoin
Mary Ziegler
Lynette Houk

In Memory of Joan Swain
Dr. Roberta Kurtz & Mrs. Hazel Kurtz

In Memory of Jean Basso
Linda Danek
Judith Batteen
Sally Beaudoin
Mary Ziegler
Lynette Houk

In Memory of Joan Swain
George Swain
Janelle Burnette

In Memory of LaRue Horst
Dr. Roberta Kurtz & Mrs. Hazel Kurtz

In Memory of Mitchell Friedlaender, MD
Lynne & Lance Forstot

In Memory of Nancy Gray
Rita Gress
Lori & Joey Moore
Amond & Linda Leigh
Jacqueline Phillips

In Memory of Natanli Sterman, PhD
Bonnie Schneider

In Memory of Patricia Ward
Charna Lefton
Anne Hickman
Jean Woods
Joan Chapel
Kathleen Presko
Dianne Criss

In Memory of Patricia Woodward
Patricia Massengill
Margaret Smith
Alan & Martha Nielson

In Memory of Ronnie Spilton
ECC Discussion Group

In Memory of Sandra Nagy
The Mustang Ladies
Kathleen Abrams

In Memory of Stan Rubin
Stephen & Deidre Perl-Strock

In Memory of Stu Satalof
Stephen & Deidre Perl-Strock

In Memory of Terri Self
Marilyn Downs-Steward
Cathy Ingels

In Memory of Tete
Delores Fritz

In Honor of Bonnie & Marc Sosin’s
25th Wedding Anniversary
Alan & Fern Rosenberg

In Honor of Dr. Archibald Skemp
Sandi Karnowski

In Honor of Dr. Cheryl Levin
Elaine & Larry Levin

In Honor of Dr. Robert Fox & Office Assistants
Linda Zarzeczny

In Honor of Jennifer Unger’s Birthday
Dad & Mom

In Honor of Leah Miller’s Birthday
Laura Grigull

In Honor of Melissa Glazer’s 30th Birthday
Carol Glazer

In Honor of Mr. & Mrs. Mort Weisenfeld’s
Birthday & Anniversary
Bert Cohen

In Honor of Nancy & David Hargrove
Elizabeth Hargrove

In Honor of Phyll Walsh
Stacy Stoutenberg

In Honor of Sheila Syty
Redeye Dog

Remember your loved ones and special occasions with a donation to the SSF in their name.
Team Sjögren’s – Goes Turkey (again)!

Turkey Trots Across America was such a success last year, that the SSF has decided to once again ask you to step up and join us this November!

We are hoping to have over 100 runners wearing Team Sjögren’s shirts on Thanksgiving Day as they run in their local hometown Turkey Trot races. Turkey Trot races happen all over the US and can range from a 1-mile fun run to a 5k race to even a 10k distance. Doesn’t matter which one you do – it’s your choice – but this is a great way to increase awareness and help the SSF raise crucial funds for Sjögren’s research and education.

You can run yourself or organize a team to run with you – either way, you will be helping us to raise awareness.

So here is how it works:

Visit www.firstgiving.com/ssf and click on Turkey Trots Across America page. On that page you will find all the information for how to set up your own personalized webpage, how to recruit a team and how to receive a Team Sjögren’s shirt to wear on race day!

Once you create your webpage, we will contact you to send you an informational pack with ideas for recruiting a team, fundraising and how to educate your local community.

We encourage you to recruit friends and family to join you at the Turkey Trot but if you can’t find anyone to join you – then run or walk yourself! What a great way to spend the day of “thanks” – Thanksgiving – than by going out and raising awareness for Sjögren’s.

If you have any questions about Turkey Trots Across America or want help in setting up your webpage – contact Ben Basloe at the Sjögren’s Syndrome Foundation at 301-530-4420, ext. 207.

Thanks for standing up and going turkey with Team Sjögren’s!
Viva Las Vegas!
Join Team Sjögren’s in Las Vegas!

Take a gamble by signing up to join our Team Sjögren’s Marathon Training Program for the Las Vegas marathon and half marathon. This program will take a walker or novice runner and prepare you to walk or run in the Las Vegas Marathon or Half Marathon!

Consider joining us for this December 2nd event where you will be able to enjoy the “Strip at Night” as we run a late afternoon marathon or half marathon with 25,000 other runners from all over the world! The marathon and half marathon course takes you up and down the Las Vegas Strip and is sure to be an amazing experience with bands along the route as well as cheerleaders to support us as we run or walk!

By signing up to join Team Sjögren’s, you not only will receive world-class training but also leadership and mentorship from past runners and staff. You will receive coaching from our Team Trainer as well as our Team Nutritionist. The staff of the SSF will help guide you through the entire process and ensure you are ready to complete either the 13.1 or 26.2-mile course!

In addition, you not only will be raising awareness for Sjögren’s but also helping raise crucial funds for Sjögren’s research and education.

We hope you will join us! If you don’t think you want to walk or run, help us recruit someone else – your husband, wife, sister, cousin, daughter, son or friend – and have them run in your honor.

We bet you can do it! Take a chance and join us. Viva Las Vegas!

To learn more about Team Sjögren’s, contact Steven Taylor at 800-475-6473, ext. 211, or staylor@sjogrens.org
Join in the fun! 2012 SSF Special Event Calendar

The SSF is very excited for all of our events coming this Fall. Look at our special event calendar below to see if there is an event coming to your area.

October

13 Capital Region Walkabout
Colonie Center Mall
Albany, New York
Registration: 10:00am
Walkabout Step-Off: 11:15am

14 Vermont Walkabout
University Mall
South Burlington, Vermont
Registration: 10am
Walkabout Step-Off: 11am

November

15 Dallas, Ft. Worth & Northern Texas Sip for Sjögren's
Whole Foods
11700 Preston Road
Dallas, Texas

22 Turkey Trots Across America
Throughout the United States
Find your local run at www.active.com
Create a team by signing up on our Turkey Trots Across America page at www.firstgiving.com/ssf website

December

2 Team Sjögren's Las Vegas Rock n' Roll Marathon
Las Vegas, Nevada

Visit www.sjogrens.org or contact the SSF office to learn more about our events!

Help to Make a Difference in your Community!

We are currently recruiting committee members for all of our events.

Please call to see if there is an event in your area (800-475-6473).