This is the second revival of an essay I wrote fifteen years ago, originally entitled, "11 Types of Fatigue." Once again, I've been asked by the Sjögren’s Foundation to give it new life. I thank them for the opportunity and hope that in the fifteen years that have passed since the original essay, there is increased acknowledgment of fatigue as a major factor in Sjögren’s and a growing knowledge that Sjögren’s is a systemic disease. My list of fatigue now numbers fifteen different subtypes. It is by no means meant to be exhaustive… the bulk of the article remains the same as it did in both 2003 and 2013.

A quick update: The friend mentioned below was my first friend with Sjögren’s and as such, has always been very special to me. We still speak in a kind of shorthand, as I do with most if not all of my Sjögren’s friends. The friends I have made over the years are the best outcome of this disease. As a group, we understand what it means to say that we are “fine.” We know that when we say we are “tired,” it means really tired, i.e. that something is going on, something out of the ordinary, beyond the everyday feelings of fatigue. "How are you?” is not a question in our general culture. It is a greeting. As such, it deserves a real answer only in those circumstances where there is an understanding that the person asking truly wants to know.


The Moisture Seekers
www.sjogrens.org

Volume 36, Issue 08 September 2018

15 Types of Sjögren’s Fatigue
Teri Rumpf, Ph.D.

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Chapter 1
Teri Rumpf, Ph.D.

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Chapter 15
Teri Rumpf, Ph.D.
For those of you who haven’t seen it, here is most of the original article with a few additions and revisions:

“How are you?” I asked a friend who has Sjögren’s. “Tired,” she said, “how are you?” “Tired,” I replied, knowing we understood each other. We were talking about a special brand of fatigue. Later that day, a friend who did not have Sjögren’s asked me the same question. “How are you?” she said. “Fine” I responded, thinking it was the simpler way to answer a basically rhetorical question.

Not everyone with Sjögren’s suffers from fatigue, but many of us do. According to the 2016 Living with Sjögren’s survey done by the SSF, fatigue was the third most prevalent and disabling symptom of Sjögren’s. For me, fatigue has been a problem more disabling than dry eyes or dry mouth. I long for normal energy and the ability to sustain activity, any activity. I long for the kind of fatigue that gets better with a good night’s sleep. I want to be able to do things spontaneously. I wish I did not have to pace myself or plan rest stops. I wish that I could just get up and go, but, reluctantly and somewhat resentfully, I know that fatigue is a permanent part of my life. Having decided that if you must live in a particular landscape, you should learn the subtleties of the territory. I’ve come up to pace myself or plan rest stops.

“Fatigue” continued from page 1

For me, fatigue has been a problem more disabling than dry eyes or dry mouth. I long for normal energy and the ability to sustain activity, any activity. I long for the kind of fatigue that gets better with a good night’s sleep. I want to be able to do things spontaneously. I wish I did not have to pace myself or plan rest stops. I wish that I could just get up and go, but, reluctantly and somewhat resentfully, I know that fatigue is a permanent part of my life. Having decided that if you must live in a particular landscape, you should learn the subtleties of the territory. I’ve come up to day but is always there. For me, there appears to be a correlation between this kind of fatigue and sed rate (ESR). When one goes up, so does the other. I don’t know how often this phenomenon occurs. I could also call this my baseline.

Correction: Pregnancy in Sjögren’s

The Moisture Seekers, Summer, 2018, Page 13

Nancy Carteron, MD, FACR

Under the congenital heart block (CHB) sub-heading, weekly Doppler fetal echocardiogram surveillance was suggested between 18 and 20 weeks, however, the suggestion was intended to be between 18 and 24 weeks. It is important to note, however, that the monitoring recommendations are evolving, and that broader ranges have been suggested by the American Heart Association (between 16 and 20 weeks, however, the suggestion was intended to be between 18 and 24 weeks). As well as Jill Bayon, MD (between 18 and 26 weeks) during her presentation at the 2018 American College of Rheumatology State-of-the-Art Clinical Symposium on neonatal lupus.
line fatigue, which fluctuates and gets better or worse. All of the following are superimposed on this basic fatigue.

**Rebound fatigue**
If I push myself too far and ignore the cues my body is sending me to stop and rest, my body will fight back. When I do more than I should, the result is an immobilizing fatigue. It comes on after the fact, i.e., do too much one day and feel it the next. If I push myself today, I very likely will have to cancel everything tomorrow. An extended period of doing more than I should day, I very likely will have to cancel everything tomorrow.

**Sudden fatigue**
This crumble and fold phenomenon makes me resemble a piece of laundry. It comes on suddenly, and I have to stop whatever I’m doing and just sit down (as soon as I can). It can happen anywhere, at any time. It is the kind of fatigue that makes me shut off the computer and know what to look for, even though I make gargantuan efforts to disguise the fact that it is happening.

**Weather related fatigue**
Not everyone has this particular talent, but I can tell that the barometric pressure is dropping while the sky remains blue and cloudless. I feel a sweeping wave, a malaise, that sometimes lifts just after the rain or snow has started. Likewise, I know when a weather front is moving away, even while torrents of water are falling from the sky. I feel a lightening in my body and begin to have more energy. This kind of fatigue is accompanied by an increase in muscle aches and joint pain.

**Molten lead phenomenon**
This fatigue is present when I open my eyes in the morning and know that it is going to be a particularly bad day. It feels as if someone has poured molten lead in my head and on all my limbs while I slept. My muscles and joints hurt and doing anything is like walking with heavy weights. It is often associated with increased symptoms of fibromyalgia and sometimes helped by heat and massage.

**Fatigue related to other physical causes**
Fatigue related to other physical causes, such as thyroid problems or anemia or other diseases superimposed on Sjögren’s. My body is tired, but my mind wants to keep going and won’t let my body rest.

**Tired-wired**
Tired-wired is a feeling that comes from certain medications, such as prednisone, too much caffeine, or too much excitement or perhaps it is just a function of Sjögren’s. My body is tired, but my mind wants to keep going and won’t let my body rest.

**Flare-related fatigue**
Flare-related fatigue is an unpredictable state of increased fatigue that can last for days or weeks. It may be caused by an increase in disease activity or an undetected infection. If the latter, it either resolves on its own, or eventually presents other signs and symptoms that can be diagnosed. Additional rest is essential to deal with this kind of fatigue, but rest alone will not necessarily improve it or make it go away. Once a flare begins, it is impossible to predict where it will go or how long it will last.

**Fatigue related to other physical causes**
Fatigue related to other physical causes, such as thyroid problems or anemia or other diseases superimposed on Sjögren’s. This kind of fatigue makes you feel that you are climbing a steep hill when you are.

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**SSF in Action!**

**SSF at the 14th International Symposium on Sjögren’s Syndrome**

The SSF was excited to participate in the 14th International Symposium on Sjögren’s Syndrome (ISSS), which took place April 18–21, 2018, in Washington, DC. In all, more than 350 attendees from the US and abroad participated in the event, which featured more than 30 oral presentations and nearly 200 scientific posters on a wide array of Sjögren’s-related topics. The symposium, themed, “Paths to Precision Diagnosis and Therapy,” was held with the primary objective of fostering successful drug development and clinical trial design for Sjögren’s.

Beyond attending sessions and networking with attendees, below are some of the ways the SSF was involved with this event:

- The SSF coordinated our neighbor exhibit for the HarmonicSS project, which was staffed by international patient representatives.
- SSF in Action!
- From left to right: Kathy Hammitt, MD, and Steven Lawrence Ford, MD
- Presentations
- Over the course of the event, the SSF was involved with two panel presentations and presented four posters. On day one, Steven Taylor moderated, and Kathy Hammitt participated in, a panel session entitled, “The Perspective of Those Affected by Sjögren’s Syndrome.” Joining them for this discussion were patient representatives from both England and the Netherlands. Steven Taylor also participated in a panel presentation on HarmonicSS, in which he, project leadership and patient representatives spoke about the great potential for this collaborative effort.
- Each of the SSF’s four selected posters were presented during three designated sessions on Friday.
Fatigue may be superimposed. Sjögren’s and fibromyalgia often co-exist, such that it is difficult to separate one from the other. Thyroid problems and anemia are both common underlying organic conditions diagnosed and treated. Many of us feel. I would take it one step further. There’s a fatigue that comes with the uncertainty of a chronic illness. It’s a debilitating fatigue born of never knowing what will come next. The chronicity of Sjögren’s can wear me down and I have to make special attempts not to let it deter me. When these attempts don’t work, I wait a while and try to find something else that distracts me from my illness.

And two new ones:

Fatigue that comes from trying to keep up with family and friends who don’t have a chronic illness

As much as I try, it just isn’t possible to keep up. I’m on a schedule that all my own, and as much as I fight it, it separates me from the people I love. I’m willing to compromise to do things their way, but my body won’t cooperate.

Doctor Fatigue

I get very tired of spending my time in waiting rooms, having lab tests, and going to doctors. I don’t understand why I didn’t say this before. I’m sure it’s self-explanatory. Enough said.

It’s difficult to explain the unnatural quality and intensity of Sjögren’s fatigue to someone whose only experience has been with what is normal. We’re not talking about the same stuff. It’s apples and oranges. Sjögren’s fatigue assaults everything I do. There isn’t a part of my life that hasn’t been touched by it. It is there even on my happiest days.

Because people don’t understand, it’s often misinterpreted. “Is it depression?” a health care professional who didn’t know much about Sjögren’s asked tensed. Was he saying it was all in my head? I began to get angry but then gave him the benefit of the doubt. I put my first reaction aside and decided he was trying to understand. I was relating something outside his frame of reference, and he was attempting to find a point with which he could identify.

When you describe Sjögren’s fatigue to someone who has never experienced it, you are asking him or her to think outside the box. You want them to understand an experience that is common to those who have Sjögren’s and many other autoimmune diseases but rare otherwise. Perhaps their first reaction will be negation or denial. While it’s always difficult to encounter expressions of disbelief, it is not uncommon. I tried to see it as an opportunity to educate.

― “No,” he said to the doctor while I was talking about depression, “I think of it as a never-ending flu that varies in intensity but never goes away.” He grimaced.

Fatigue impairs concentration

Fatigue impairs concentration, precludes thought, and makes me too tired to talk, think or read. Fatigue robs me of memory and encloses me in a fog of wool. I can’t find my way out until the fog miraculously lifts. For me, brain fog goes hand-in-hand with other kinds of pernicious fatigue.

Stress, distress, anxiety or depression

Stress, distress, anxiety or depression all create a leader kind of emotional fatigue that can be as exhausting as one due to physical causes. Although some people do not associate their increased fatigue with emotional states, many are aware of the effects of increased anxiety and depression, even if they cannot control what they feel. Intense emotion is very draining. Stress, anxiety and depression all are known to disrupt sleep.

Fatigue that comes from not sleeping well

Some people with Sjögren’s have trouble both getting to sleep and staying asleep. Some wake up in the morning feeling as if they had never slept at all. Many aspects of Sjögren’s affect sleep: being too dry, too much pain or malaise; multiple trips to the bathroom, the need for water or to put in eye ointment all deter a good sleep. Lack of restorative sleep increases fatigue. Fibromyalgia worsens when you don’t get a good night’s sleep. Chronic pain increases fatigue.

Fatigue that comes with normal aging

I’m old enough for Medicare now and my friends are more tired too, although they seem to be able to do two or three or even four times what I can do on any given day. In fact, the gap between what they can do and what I can do just seems to be growing, despite my best efforts. It’s been a long time since I tried to keep up, but it still hurts that I can’t.

Fatigue that comes from a chronic illness that just won’t quit

We’ve all heard the expression “sick and tired of being sick and tired” and that phrase truly captures what many of us feel. I would take it one step further. There’s a fatigue that comes with the uncertainty of a chronic disease. It’s a debilitating fatigue born of never knowing what will come next. The chronicity of Sjögren’s can wear me down and I have to make special attempts not to let it deter me. When these attempts don’t work, I wait a while and try to find something else that distracts me from my illness.
1983
Foundation was founded by Elaine K. Harris

1984
First SSF Newsletter published

1985
Foundation was incorporated

1986
First International Symposium (Copenhagen, Denmark)

1989
Syndrome” conference
Faces of Sjögren’s released

1991
First SSF Research Grant made

1992
The Moisture Seekers newsletter first published

1996
First International Symposium on Sjögren’s Syndrome (ISSS) (Copenhagen, Denmark)

1999
First SSF Student Fellowship awarded

1998
April declared Sjögren’s Awareness Month by Congress

2000
First SSF Student Conference (Los Angeles)

2001
First SSF National Patient Conference held by Bethesda, Maryland

2002
First time Sjögren’s was included in Congressional Appropriations language

2003
American European Diagnostic Criteria published

2004
Restasis® approved by the FDA

2005
First SSF Quarterly first published

2006
First SSF Research Grant made

2007
First SSF Student Conference held by Bethesda, Maryland

2008
First SSF National Patient Conference held by Bethesda, Maryland

2009
First SSF Research Grant made

2010
First SSF National Patient Conference held by Bethesda, Maryland

2011
First SSF Research Grant made

2012
First SSF Research Grant made

2013
First SSF Research Grant made

2014
First SSF Research Grant made

2015
First SSF Research Grant made

2016
First SSF Research Grant made

2017
First SSF Research Grant made

2018
First SSF Research Grant made

The average time to diagnosis Sjögren’s is reduced to 3.5 years!
Celebrating 35 Years in the Fight Against Sjögrens!

After being diagnosed with Sjögren’s in 1983, Elaine Harris was frustrated that it took so long to identify the symptoms she was experiencing and discouraged by the lack of information that existed about the disease. Determined initially to simply meet other patients and start a support group, Elaine ended up achieving so much more.

35 years later, the mission and core values of the Sjögren’s Syndrome Foundation (SSF) remain the same while we have also grown into a multi-faceted organization that has expanded its outreach, increased its funding for research and education, and has significantly improved awareness about this complex disease.

The reason for the SSF’s longevity, growth and continued achievements are because of the contributions of countless dedicated volunteers, board members, generous donors and other supporters. It has been your ideas and input, your questions and your appetite for more of what we do—determined and growing year by year—that has allowed the SSF to continue to strengthen and grow.

The SSF is extremely honored to serve as the voice for all Sjögren’s patients. Our initiatives, programs and overall efforts are first and foremost started, advanced and expanded with the Sjögren’s patient in mind.

The SSF’s goal is to alleviate patients’ concerns and provide them with a sense of hope. With so many people living in trepidation of their disease progressing, we want to make a difference for patients and provide them with a sense of hope now and for the future. Hope that patients are diagnosed sooner, receive the best possible treatment they need and deserve, and are able to improve their quality of life.

It is truly remarkable how far the Foundation has come in the past 35 years and how many people have been helped but just imagine how much more can be accomplished in the years to come.

Help us celebrate our accomplishments and continue on our journey of conquering Sjögren’s by donating in honor of our 35th Anniversary below.

IT’S TIME

United Way • Combined Federal Campaign • State Payroll Deduction

Each year 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 (CFC #10603)

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(c)(3) organization and qualify for most payroll deduction campaigns. If they need more information, please contact the Foundation at 800-475-6473.

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.

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$35 $100 $250
$500 $1,000 Other $ ___________

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Remember, the Foundation has invested in you and is making a difference in the lives of those living with Sjögren’s. You have the power to make a difference in the lives of those living with Sjögren’s. Additionally, the SSF is extremely honored to serve as the voice for all Sjögren’s patients. Our initiatives, programs and overall efforts are first and foremost started, advanced and expanded with the Sjögren’s patient in mind.

The SSF’s goal is to alleviate patients’ concerns and provide them with a sense of hope. With so many people living in trepidation of their disease progressing, we want to make a difference for patients and provide them with a sense of hope now and for the future. Hope that patients are diagnosed sooner, receive the best possible treatment they need and deserve, and are able to improve their quality of life.

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Help us celebrate our accomplishments and continue on our journey of conquering Sjögren’s by donating in honor of our 35th Anniversary below.

Meetings
The SSF took advantage of the many international Sjögren’s experts and patients being together in one place and led two meetings during the ISSS. First, a meeting of the International Sjögren’s Network took place on Friday, April 20, 2018, which included more than 20 attendees from around the world who took the time to discuss group activities and ways in which the group can continue to strengthen and grow.

Second, at the conclusion of the ISSS, the SSF held a meeting of the Clinical Trials Consortium Steering Committee in which the attendees received updates on a variety of important SSF-led initiatives.

There were a lot of great things to take from this event and we’re now looking forward to the next ISSS, which will take place in Rome, Italy, in 2021.
Interview with Elaine K. Harris, SSF Founder

Steven Taylor and Elaine Harris at the SSF 30th Anniversary Celebration in 2013

Like many newly diagnosed patients, Elaine K. Harris was frustrated with the lack of information available about her disease. Without a Foundation or the internet, Elaine was only able to find two patient fact sheets that mentioned the disease. Determined to take control of her health and learn more about her symptoms, Elaine used her past community involvement to start a local support group with only one other Sjögren’s patient that she met, the secretary of her doctor. She then slowly grew that support group into the Sjögren’s Syndrome Foundation (SSF).

Today, the Foundation serves thousands of patients and has grown into a powerhouse organization, breaking down barriers worldwide in the field of Sjögren’s. The many achievements that the SSF has seen in the last 35 years is because of the hundreds of volunteers and members across the country. Although none of what we have today would be possible if it wasn’t for Elaine turning her frustration into a source of hope for all patients.

This August, Elaine Harris and Janet Church, the new Chairman of the SSF Board of Directors, had the opportunity to meet and discussed the past, present and future of the Foundation. Below are excerpts from their interview.

What was your key motivation as to why you started the Foundation?
I wanted more people to know about Sjögren’s, to be able to talk to other patients and have more doctors interested in it.

How do you think the Foundation is doing today?
I think the Foundation is doing superbly.

What was the primary focus of the SSF in its earliest days?
There was a need for doctors who could recognize the discrete manifestations as possibly related symptoms. We wanted to develop and distribute patient-oriented literature that would also help doctors communicate with each other regarding the patient’s needs and proposed treatment.

We also saw a great need for promoting public awareness about Sjögren’s and getting more physicians interested so that they would focus on developing treatments, bringing relief to patients.

How did the newsletter receive the name, The Moisture Seekers?
Name recognition is a challenge with Sjögren’s. It’s a disease name that people cannot easily pronounce or spell. We reasoned that since we were looking for moisture for the many organs in our body, naming our group The Moisture Seekers made sense.

When were ready to incorporate as an official “not-for-profit organization,” our lawyer suggested it would be best to name the organization after the disease. We decided to become the “Sjögren’s Syndrome Foundation” but I didn’t want to let the name The Moisture Seekers go and retained it for the newsletter.

Why do you think it’s important for patients to add their voice to the SSF?
The squeaky wheel gets oiled. Sjögren’s patients take time and doctors are often limited with time. This is why it’s so important to learn from doctors through the SSF newsletter, local support group meetings and the National Patient Conferences.

It is also important to help educate your doctor and not be bashful when talking about your disease. You have to spread the word and keep trying for those who are living with debilitating manifestations and find it difficult to function.

What is the best advice that you would give to a new diagnosed patient?
Meet other Sjögren’s patients. Patients will talk to each other about some of their problems that they are reluctant to bring up to doctors.

Find a doctor who is informed about the many manifestations of Sjögren’s or one who will work with you and is interested in learning. Someone who will listen to your problems, communicate with the other specialists treating you, and keep up with the new medications being developed to treat the disease.

What advice would you like to share with all patients?
Be open about your Sjögren’s and never stop reaching!

What is the biggest transformation between the early years of the SSF to now?
Growth in the pharmaceutical industry. Today it seems possible that there’s a pot of gold to be found!

J
Elaine K. Harris (center)

anet Church has served as a member of the Board of Directors for six years and throughout that time has offered her expertise as an entrepreneur, tech-industry veteran and a Sjögren’s patient, a key member and volunteer of the foundation. We are honored to have Janet as the new Chairman of the Sjögren’s Syndrome Foundation Board of Directors.

“It was a joy to talk to the woman who has been carrying the patient flag for all of us for the past 35 years. As the new SSF Chairman and having been diagnosed with Sjögren’s for 12 years, I look forward to the many direct patient-to-patient conversations we will have in the upcoming years and promise to do my best to carry the flag!”

For me, I felt that getting involved with the Foundation was a way that I could help myself the most. I feel that it is better to Stay Active, Stay Informed and Attempt to Do Something, than to not do something. I am inspired by all that the SSF has accomplished and I am personally excited, as well as honored, to be leading us over the next two years.”
35th Anniversary Special
Top 5 SSF Resources

The Sjögren’s Syndrome Handbook
by Terri F. Trumpf, PhD and Katherine Roland-Strnad (F: It’s About a Lifetime Book)
Member Price: $28
Non-Member Price: $32

The Immune System Recovery Plan: A Doctor’s 6-Step Program to Treat Autoimmune Disease
by Howard Husock and Robin Henschel (2nd edition)
Member Price: $22
Non-Member Price: $25

The Sjögren’s Syndrome Survival Guide
by Daniel J. Wallace, MD
Member Price: $20
Non-Member Price: $32

You Can Cope With Peripheral Neuropathy: 365 Tips for Living a Full Life
by Mims Cushing and Norman Latov, MD

Set of 7 Audio CDs from the NPC 2018
by Mims Cushing and Norman Latov, MD

These books can be purchased using the order form below, online at www.sjogrens.org/store or by contacting the Sjögren’s Syndrome Foundation office at 800-475-6473.

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☑ MasterCard ☑ VISA ☑ Discover ☑ AmEx Card Number ____________________________ Exp. Date __________
Signature ____________________________ CC Security Code ____________________________
If you would like to receive this newsletter but are not currently an SSF Member, please contact us! 800-475-6473

Team Sjögren’s Goes Turkey!

This Thanksgiving, we hope you will consider participating in your community Turkey Trot as a member of Team Sjögren’s!

What a great way to start your day of giving thanks – by purchasing a Team Sjögren’s Turkey Trot Kit and walking or running with others in your area, increasing awareness for Sjögren’s and helping raise crucial funds for Sjögren’s research.

You can find a local Turkey Trot by visiting www.active.com or in your local newspaper. If there isn’t one in your area, consider creating your own Turkey Trot! Ask family and friends to join you for a morning walk in your neighborhood or at a nearby park on Thanksgiving morning while wearing your Team Sjögren’s T-shirts!

Order your Team Sjögren’s Turkey Trot Kit by calling 800-475-6473 or online at www.sjogrens.org.

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<th>Size: S-2XL</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Team Sjögren’s Turkey Trot T-Shirt</td>
<td>20 ea.</td>
<td></td>
</tr>
<tr>
<td>Single Person Team Sjögren’s Turkey Trot Kit</td>
<td>35 ea.</td>
<td></td>
</tr>
</tbody>
</table>

Shipping and Handling:
- U.S. Mail: $5 for first item + $3 for each additional item
- Canada: $14 for first item + $3 for each additional item
- Overseas: $22 for first item + $3 for each additional item

Total Amount Due

Mail to SSF: BB&T Bank • PO Box 890612 • Charlotte, NC 28289-0612
or Fax to: 301-530-4415

Name ____________________________________________
Address __________________________________________
City __________________ State _______ Zip ________
Telephone __________________ E-Mail __________________

☐ Enclosed is a check or money order (in U.S. funds only, drawn on a U.S. bank, net of all bank charges) payable to SSF.

☐ MasterCard  ☐ VISA  ☐ Discover  ☐ AmEx  Card Number ____________________________
Exp. Date ______ Security Code ______ Signature ____________________________