



*2009 Annual Report*



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LFA Alaska Chapter

P.O. Box 240628  
Anchorage, Alaska, 99524-0628

800 307-5878  
907 338-6332

[www.lupusalaska.org](http://www.lupusalaska.org)

# LUPUS FOUNDATION OF AMERICA

## ALASKA CHAPTER

### 2009 ANNUAL REPORT

The **Lupus Foundation of America (LFA) Alaska Chapter** was founded in July of 1986 as a nonprofit, nonsectarian, primarily volunteer organization. Our chapter is affiliated with and receives organizational support from the Lupus Foundation of America (LFA), the nation's leading non-profit voluntary health organization dedicated to research, education and advocacy in finding the causes of and cure for lupus.

The **Alaska Chapter** of LFA, serving over 40 cities and communities in Alaska, strives to improve early diagnosis and treatment of lupus, support individuals, families and friends affected by the disease, and increase awareness of lupus among health professionals and the public. We do this through our strong and involved Board of Directors and our dedicated and committed volunteers.

## About Lupus

It is estimated that lupus affects 1.5 million Americans nationally and over **3,000 Alaskans**. Lupus is a widespread life diminishing and potentially life threatening disease that causes the immune system to attack the body's own healthy tissues and organs, including the kidneys, heart, lungs, brain, blood, and skin. Common symptoms of lupus include joint pain and swelling, fevers, extreme fatigue, skin rashes, anemia, chest pains due to inflammation of the heart or lungs, and sun sensitivity, among others.

Without intervention, the number of people nationally with lupus is expected to rise to more than 2 million in the next decade. The disease is two to three more common among African Americans, Hispanics, Asians and Native Americans. While eight of the ten new cases of lupus develop among women of childbearing age, men and women of all ages, as well as children also develop the disease. At the present time, there is not a cure for lupus.

Lupus is NOT infectious, rare, or cancerous. Researchers do not know exactly what causes lupus. While scientists believe there is a genetic predisposition to the disease, it is known that environmental factors such as sun exposure, stress, toxins, and infections can play a role in triggering the disease.



## Shelly's Story

In every family there is some trait passed along the generations that is recognized as a 'common thread' among members. Some families get Grandpa's eyes; some get Great Aunt Millie's dry sense of humor. For my family, our common trait is lupus.

When my mother was first diagnosed at 35, we knew very little about the disease other than the muscle pain she suffered on a regular basis. We learned more throughout the years as not one but every female member of my family was diagnosed. After my mom came my aunt, her

daughter and, finally, my diagnosis at the age of 20. We have varying degrees of the disease, from my general fatigue and muscle aches to the full-blown multi-organ involvement that eventually claimed my 31 year old cousin's life. At any level it is a disease that touches and changes us all.

While no one wishes for a chronic and life threatening illness, I am grateful that the disease I have is one that, so far, has been treatable and tolerable. I take my medication each day as my only major treatment. Experience has taught me that controlling my weight and getting regular exercise and sleep can alleviate the need for the two prescription pain killers and muscle relaxers I took each day in my early twenties. Yet I am, like all lupus patients, always cautious about the road ahead and the challenges I may face. Any fever is one to question. Vacations and trips must always allow for rest and sleep, otherwise I can count on a forced "time out" from a flare. How will this affect my family life when my husband and I decide to have kids? Will my boss understand when I can't "push through" a simple cold at work like the rest of my co-workers? Issues which, for me, are mere complications become full battles for those with more severe cases.

# ***WHAT WE DO***

## **SUPPORT**

- Organize and facilitate support groups for individuals with lupus and their families
- Provide phone support through local and toll free numbers: (907) 338-6332 and (800) 307-5878
- Provide a website with information regarding our local chapter, lupus, support options, and links to the national LFA web site
- Supply brochures, books and resource articles about lupus to individuals with lupus and their families
- Maintain a lending library of books, videos and over 600 articles
- Distribute newsletter ***LUPUS LINK*** and national LFA magazine ***LUPUS NOW*** to our Alaska Chapter members
- Provide assistance and information to requesting individuals on current lupus treatment, diagnosis and physician referrals (both within Alaska and nationally)

## **EDUCATION & AWARENESS**

- Provide Lupus related brochures, newsletters, books and current literature to individuals as well as the Alaska medical community statewide; including doctors, clinics, nurse practitioners, dentists and chiropractors
- Present lupus information at health fairs, businesses, and conferences
- Organize continuing education opportunities on the topic of lupus for physicians, nurses, health aides, dentists, dental hygienists, and chiropractors



***Cities and communities where  
LFA Alaska has members and  
provides services***



# Highlights and Accomplishment for 2009

**Walk for Lupus Now** – On September 19, 2009, the Alaska Chapter hosted the State's first Walk for Lupus Now™, a nation-wide fundraising event aimed at raising both money and awareness of this chronic and debilitating disease. The National LFA provided a grant to assist in planning and implementation of the event. Over 125 walkers and 240 donors supported the Walk for Lupus Now™ held at the Alaska Dome. The event raised \$25,000 in cash and in-kind donations.



*Team Alaska*

*Individuals and teams on the start line*



**2<sup>nd</sup> Wine Tasting and Silent Auction** – This successful fundraising event was held in partnership with Wine Styles on April 24<sup>th</sup> at O'Malleys on the Green and raised \$7,000.

**Jammin Salmon" Cook Off** - The Eagle River Chugiak Chamber of Commerce's IBEW Salmon Cook-Off at the Bear Paw Festival in July 2009 chose the LFA Alaska Chapter as the recipient charity for this annual fundraiser.

**Health Fairs** - Alaska Chapter volunteers participated in **23** Health Fairs in the communities of Anchorage, Wasilla, Palmer, Fairbanks, Seward, Girdwood and Nome.

### **Day of Caring –**

ConocoPhillips IT Department volunteered their time and office for the 7<sup>th</sup> year in a row by preparing a mass mailing of informative letters to Alaska medical providers and post cards promoting our chapter's the *Walk for Lupus Now*<sup>™</sup>, as well as putting together the gift bags for the Walk.



**Volunteers** – Over **10,000** hours were provided Statewide by wonderful dedicated community volunteers supporting the Alaska Chapter of LFA.

**Lupus Link** – The quarterly multipage Alaska Chapter newsletter was produced and distributed to nearly 500 LFA Alaska Chapter members as well as medical professionals and clinics Statewide.

### **Additional Awards, Grants & Donations**

**Alaska Kidney Association** - award grant for \$1,200 to assist the chapter in buying educational materials

**Rasmuson Foundation** – award grant for \$14,864 to purchase office technical equipment and furnishings

**Alaska Permanent Dividend** –“*Pick, Click and Give*” – individual donations of \$800

**Payroll Deduction Program including Alaska Community Share / United Way / Combined Federal Campaign** – donations of \$2,198

**KeyBank Leadership Grant** – award grant of \$500

**Leadership Anchorage** – selected LFA Alaska Chapter as one of four community projects for the 2009-2010 class. This project will assist in the development of a new business plan to reach and support the younger lupus population of Alaska as well as the broader lupus community in the State.

**Jackie G. Page Charitable Trust** – donation of \$17,000 to be applied towards an Alaskan Statewide Lupus Conference

**Lupus Foundation of America** – award grant of \$11,000 for the implementation of the first *Walk for Lupus Now* in Alaska





### Debora's Story

I have been living with lupus for 40 years. Lupus and other auto-immune diseases run in families, so my daughter and granddaughter are at increased risk of developing lupus. On average, it takes 1 - 4 years and visits to 3 doctors before patients are correctly diagnosed with lupus. For me, it took over 26 years and a multitude of doctors before I received a diagnosis of lupus.

*L to R -granddaughter Keely, Debora and daughter Michelle*

This is my story:

At seventeen, I had a horrible rash everywhere on my body. The doctor said it was an allergic reaction. At twenty, I started having transient strokes that caused temporary loss in my visual field. The doctor said to quit taking birth control pills. In my twenties, I also had several miscarriages. In my thirties, I often felt fatigued and was hospitalized for 4 days for high fevers of unknown origin. The doctors couldn't find anything wrong with me. Finally, at age 43, I went to my doctor and complained of severe fatigue. He asked me if I was depressed (which I wasn't) and said to come back in a month if I was still feeling fatigued. A month later, I finally got a diagnosis. It was a relief to finally know what had been causing all of my medical problems.

Living with any chronic and potentially life-threatening illness is a challenge. People with lupus often have to quit working because of the overwhelming fatigue combined with the unpredictable nature of the illness. After 25 years as a dental hygienist, I had to give up my work and my wonderful patients. Lupus also makes it difficult to pursue my love of gardening since being in the sun causes flare-ups of the disease. Although lupus has taken several things from me, it has also inspired me to be a better person and to live each day to the best of my ability. I volunteer my time with the Lupus Foundation of America Alaska Chapter and Big Brothers Big Sisters. My life is full of wonderful experiences and I am blessed to have amazing friends and family to support me.

# **Business and Community Support**

- **Alaska Printing**
- **Alaska Serigraphics**
- **CRW Engineering Group LLC**
- **Denali Alaska Federal Credit Union**
- **Key Bank**
- **Specialty Imports**
- **The Alaska Club**
- **The Alaska Dome**
- **Wine Styles**
- **ConocoPhillips**
- **Alaska Pure Water Products**
- **Fred Meyer**
- **Sugar Spoon Bakery**
- **Starbucks**
- **Great Harvest Bakery**
- **The Event Divas**
- **Alaska Mill and Feed**
- **Sacks**
- **Snow City Café**
- **Yak and Yeti Restaurant**
- **Allure Day Spa**
- **Marx Brothers Restaurant**
- **Heritage Coffee Company**
- **Alaska Brewing Company**
- **Title Wave**
- **Alaska Railroad**
- **Southside Bistro**
- **The Frame Workshop and Gallery**
- **Doriolas**
- **Corsair**
- **Marian Call**
- **Alaska Railroad**

# Board of Directors

**Judy Powell – Board Chair**

2143 Churchill  
Anchorage, AK 99517  
907-272-6390 home  
907-229-4132 cell  
[planepowell@gci.net](mailto:planepowell@gci.net)  
Service started 2/09, Expires 2/12

**Joyce Schuerger**

8441 Stacy Circle  
Anchorage, AK 99507  
907-344-3746  
[sugarshack@gci.net](mailto:sugarshack@gci.net)  
Service re-started 2/09, Expires 2/12

**Shelly Ciarella- Vice-Chair**

17527 Silverwood Way  
Eagle River, AK 99577  
907-242-7345 cell  
[scirarella@yahoo.com](mailto:scirarella@yahoo.com)  
Service started 9/07, Expires 2/11

**Christine Hess**

c/o Rep. Joule, State Capitol Bldg  
Room 421  
Juneau, AK 99801  
907-465-4833 work  
[christine\\_hess@legis.state.ak.us](mailto:christine_hess@legis.state.ak.us)  
Service started 9/08, Expires 2/12

**Billie DeVore - Treasurer**

PO Box 220422  
Anchorage, AK 99520-0422  
907-272-3727 home/work  
[billie.d@att.net](mailto:billie.d@att.net)  
Service started 9/06, Expires 2/10

**Dawn Harrison**

4255 Old Seward Highway Apt 12  
Anchorage, AK 99508  
907-982-2375 home  
[wren1313@yahoo.com](mailto:wren1313@yahoo.com)  
Service started 10/09

**Debora Griffeth – Past Chair**

1631 George Bell Circle  
Anchorage, AK 99515-3955  
907-345-3356 home  
907-440-7047  
[griffethinalaska@yahoo.com](mailto:griffethinalaska@yahoo.com)  
Service started 9/98, Expires 2/10

**Barb Madden – Secretary**

6440 Gunnison Drive  
Anchorage, AK 99516  
907-868-2777  
[barbmadden@aol.com](mailto:barbmadden@aol.com)  
Service started 10/09

**Roger Hyde**

3104 Northwood Drive  
Anchorage, AK 99517  
907-277-0257 home  
907-727-6933 cell  
[hydenout@gci.net](mailto:hydenout@gci.net)  
Service started 9/03, Expires 2/10