

SCR

1

<TARGET><BILL>SCR 1</BILL><SUBJECT>SCR
1</SUBJECT><COMM>HHSS27</COMM></TARGET>

Alaska State Legislature

Senate
Health & Social
Committee
Chair
•
Senate
Education Committee
Vice-Chair



Legislative Council
Vice-Chair
•
Senate
Transportation
Committee
•
Senate
Labor & Commerce
Committee

[Senator Bettye Davis@legis.state.ak.us](mailto:Senator_Bettye_Davis@legis.state.ak.us)
<http://www.aksenate.org/>

Senator Bettye Davis

Date: April 7, 2011

To: Representative Wes Keller
Chair, House Health & Social Services Committee

From: Senator Bettye Davis *BD*

RE: Hearing request for "SCR1 Designating May as Lupus Awareness Month"

Representative Keller,

You currently have in your possession SCR1 – "Designating May as Lupus Awareness Month" and I am respectfully requesting this resolution be scheduled for a hearing in House Health & Social Services Committee quickly in order to designate this May as Lupus Awareness Month to show support for more 3,000 Alaskans diagnosed with lupus.

Lupus is a disease that affects the immune system by causing inflammation and tissue damage. Major gaps exist in the understanding of the causes and consequences of lupus. Lupus can affect any body part, including the skin, lungs, heart, kidney, and brain. Lupus can cause seizures, strokes, heart attacks, miscarriages and organ failure. Lupus strikes mostly women of childbearing age and women of color develop lupus at a rate two-to-three times the rate that Caucasians develop lupus. Lupus is difficult to diagnose because its symptoms are similar to symptoms of other illnesses. It's been 50 years since the U.S. Food and Drug Administration approved a medication specifically for lupus and treatment for lupus can have damaging side effects.

By designating May as Lupus Awareness Month, Alaska will join other states to help increase awareness of lupus and show support for the more than 1.5 million Americans diagnosed with the disease. Please contact Celeste Hodge at 465-4906 if you have any questions relating to this request. Thank you.

Alaska State Legislature

Interim: (May - Dec.)
716 W. 4th Ave
Anchorage, AK 99501
Phone: (907) 269-0144
Fax: (907) 269-0148



Session: (Jan. - May)
State Capitol, Suite 30
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Senator Bettve Davis@legis.state.ak.us
<http://www.akdemocrats.org>

Senator Bettve Davis

SCR1 "Designating May as Lupus Awareness Month"

SPONSOR STATEMENT

SCR1 designates May as Lupus Awareness Month and encourages Alaskans to observe Lupus Awareness Month with appropriate activities that provide both lupus education and support for people diagnosed with the disease.

According to the Lupus Foundation of America, lupus is an acute, chronic and often lifelong disease affecting the immune system by causing inflammation and tissue damage. Major gaps exist in the understanding of the causes and consequences of lupus. Lupus can affect any body part, including the skin, lungs, heart, kidney, and brain. Lupus can cause seizures, strokes, heart attacks, miscarriages and organ failure. Lupus strikes mostly women of childbearing age and women of color develop lupus at a rate two-to-three times the rate that Caucasians develop lupus. Lupus is difficult to diagnose because its symptoms are similar to the symptoms of other illnesses. New drugs have not been approved by the United States Food and Drug Administration specifically for lupus during the last 50 years. Current treatment for lupus can have damaging side effects.

Each year, May is designated as Lupus Awareness Month to show support for the estimated 1.5 million Americans with lupus. More than 3,000 cases of lupus have been diagnosed in Alaska in patients 20 to 87 years of age. Ten members of the Lupus Foundation of America, Alaska Chapter recently passed away from lupus. Designating May as Lupus Awareness Month will help increase awareness of lupus and show support for those diagnosed with the disease.

FISCAL NOTE

STATE OF ALASKA
2011 LEGISLATIVE SESSION

Fiscal Note Number 1
 Bill Version CSSCR 1(STA)
 (S) Publish Date 3/9/11

Identifier (file name) _____ Dept. Affected _____
 Title SCR 1 LUPUS AWARENESS MONTH Appropriation _____
 Allocation _____
 Sponsor Senator Davis _____
 Requester _____ OMB Component Number _____

Expenditures/Revenues (Thousands of Dollars)

Note: Amounts do not include inflation unless otherwise noted below.

	Appropriation Required	Information					
		FY 2012	FY 2013	FY 2014	FY 2015	FY 2016	FY 2017
OPERATING EXPENDITURES							
Personal Services							
Travel							
Services							
Commodities							
Capital Outlay							
Grants							
Miscellaneous							
TOTAL OPERATING	0.0	0.0	0.0	0.0	0.0	0.0	0.0

CAPITAL EXPENDITURES							
-----------------------------	--	--	--	--	--	--	--

CHANGE IN REVENUES							
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FUND SOURCE (Thousands of Dollars)

1002 Federal Receipts							
1003 GF Match							
1004 GF							
1005 GF/Program Receipts							
1037 GF/Mental Health							
Other (please identify)							
TOTAL	0.0	0.0	0.0	0.0	0.0	0.0	0.0

Estimate of any current year (FY2011) cost _____

POSITIONS

Full-time							
Part-time							
Temporary							

Why this fiscal note differs from previous version (if initial version, please note as such)

Prepared by SENATE STATE AFFAIRS COMMITTEE
 Division _____
 Approved by /s/ Senator Wielechowski, Chair

Phone 465-2435
 Date/Time 3/8/11 12:00 AM
 Date _____

FISCAL NOTE #1

STATE OF ALASKA
2011 LEGISLATIVE SESSION

BILL NO. CSSCR 1(STA)

Analysis

No Fiscal Impact.

FISCAL NOTE

STATE OF ALASKA
2012 LEGISLATIVE SESSION

Bill Version CSSCR 1 (STA)
 Fiscal Note Number _____
 () Publish Date _____

Identifier (file name) CSSCR1STA-LEG-COU-2-17-12 Dept. Affected Legislature
 Title "Designating May of each year as Lupus Awareness Appropriation Legislative Council
Month." Allocation Council & Subcommittees
 Sponsor Senator Davis, Representative Holmes
 Requester Health & Social Services OMB Component Number 783

Expenditures/Revenues (Thousands of Dollars)

Note: Amounts do not include inflation unless otherwise noted below.

	FY13 Appropriation Requested	Included in Governor's FY13 Request	Out-Year Cost Estimates				
			FY14	FY15	FY16	FY17	FY18
OPERATING EXPENDITURES	FY13	FY13	FY14	FY15	FY16	FY17	FY18
Personal Services							
Travel							
Services							
Commodities							
Capital Outlay							
Grants, Benefits							
Miscellaneous							
TOTAL OPERATING	0.0	0.0	0.0	0.0	0.0	0.0	0.0

FUND SOURCE		(Thousands of Dollars)					
1002	Federal Receipts						
1003	GF Match						
1004	GF						
1005	GF/Prgm (DGF)						
1037	GF/MH (UGF)						
1178	temp code (UGF)						
TOTAL		0.0	0.0	0.0	0.0	0.0	0.0

POSITIONS							
Full-time							
Part-time							
Temporary							

CHANGE IN REVENUES							
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Estimated **SUPPLEMENTAL (FY12) operating costs** _____ (separate supplemental appropriation required)
 (discuss reasons and fund source(s) in analysis section)

Estimated **CAPITAL (FY13) costs** _____ (separate capital appropriation required)
 (discuss reasons and fund source(s) in analysis section)

Why this fiscal note differs from previous version (if initial version, please note as such)

Initial Version

Prepared by Jessica Geary, Finance Manager Phone 465-6626
 Division Legislative Affairs Agency Date/Time 2/17/12 10:38 AM
 Approved by Pamela Varni, Executive Director Date 2/17/2012
Legislative Affairs Agency

FISCAL NOTE

**STATE OF ALASKA
2012 LEGISLATIVE SESSION**

BILL NO. CSSCR 1 (STA)

Analysis

This Legislation has zero fiscal impact on the Legislative Affairs Agency.

Alaska State Legislature



Senate
Health & Social
Committee
Chair
•
Senate
Education Committee
Vice-Chair


Legislative Council
Vice-Chair
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Senate
Transportation
Committee
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Senate
Labor & Commerce
Committee

[Senator Betty Davis@legis.state.ak.us](mailto:Senator_Betty_Davis@legis.state.ak.us)
<http://www.aksenate.org/>

Senator Bettye Davis

Date: January 31, 2012

To: Representative Wes Keller
Chair, House Health & Social Services Committee

From: Senator Bettye Davis 

RE: Hearing request for "SCR1 Designating May as Lupus Awareness Month"

Representative Keller,

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By designating May as Lupus Awareness Month, Alaska will join other states to help increase awareness of lupus and show support for the more than 1.5 million Americans diagnosed with the disease. Please contact Celeste Hodge at 465-4906 if you have any questions relating to this request. Thank you.



2009 Annual Report


LUPUS[™]
Foundation of America
Alaska Chapter, Inc.



2009 Annual Report

LFA Alaska Chapter

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

800 307-5878
907 338-6332

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



2nd Wine Tasting and Silent Auction – This successful fundraising event was held in partnership with Wine Styles on April 24th 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 7th 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™*, 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 Cali**
- **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
Service started 2/09, Expires 2/12

Joyce Schuerger
8441 Stacy Circle
Anchorage, AK 99507
907-344-3746
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
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
Service started 9/08, Expires 2/12

Billie DeVore - Treasurer

PO Box 220422
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907-272-3727 home/work
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Service started 9/06, Expires 2/10

Dawn Harrison
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907-982-2375 home
wren1313@yahoo.com
Service started 10/09

Debora Griffeth – Past Chair

1631 George Bell Circle
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907-345-3356 home
907-440-7047
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
Service started 10/09

Roger Hyde

3104 Northwood Drive
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907-277-0257 home
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hydenout@gci.net
Service started 9/03, Expires 2/10

Lupus Foundation of America, Inc.

What I Need to Know About Lupus

If you have been diagnosed with lupus, you will want to know as much as you can about the disease. Lupus is a chronic, autoimmune disease that can damage any part of the body (skin, joints, and/or organs inside the body). Normally the immune system produces proteins called antibodies that protect the body from foreign invaders, such as bacteria and viruses. With lupus, the immune system cannot tell the difference between these foreign invaders and the body's healthy tissues and creates autoantibodies ("auto" means "self") that attack and destroy healthy tissue. These autoantibodies cause inflammation, pain, and damage in various parts of the body.

Lupus is a disease of flares (the symptoms worsen and you feel ill) and remissions (the symptoms improve and you feel better). Lupus can range from mild to life-threatening and should always be treated by a doctor. With good medical care, most people with lupus can lead a full life.

What Causes Lupus?

No one knows what causes lupus. However, scientists believe that hormones, genetics (heredity), and environment are all involved. Hormones regulate many of the body's functions. In particular, the sex hormone estrogen is believed to play a role in lupus. Men and women both produce estrogen, but estrogen production is much greater in females.

Understanding
LUPUS

Understanding LUPUS

Scientists have noted some common triggers among people who have lupus, including exposure to the sun, an infection, a medication taken to treat an illness, pregnancy, and giving birth.



However, that does not mean that estrogen, or any other hormone for that matter, causes lupus.

While no gene or group of genes has been proven to cause lupus, the disease does appear in certain families. And, although lupus can develop in people with no lupus in their family

What I Need to Know About Lupus

history, other autoimmune diseases may be present in some family members. Certain ethnic groups (people of African, Asian, Hispanic/Latino, Native American, or Pacific Island descent) have a greater risk of developing lupus, which may be related to genes they have in common.

Your genes may increase the chance that you will develop lupus, but scientists believe some kind of environmental trigger can set off the illness or bring on a flare, such as:

- ❖ *ultraviolet rays from the sun or from fluorescent light*
- ❖ *sulfa drugs and some tetracycline drugs, which make a person more sensitive to the sun*
- ❖ *penicillin or certain other antibiotic drugs*
- ❖ *infection*
- ❖ *a cold or a viral illness*
- ❖ *exhaustion*
- ❖ *injury*
- ❖ *emotional stress*
- ❖ *anything that causes stress to the body such as surgery, an accident, pregnancy, or giving birth*

Facts About Lupus

- ❖ *Lupus is not contagious.*
- ❖ *Lupus is not like or related to cancer.*
- ❖ *Lupus is not like or related to HIV or AIDS.*
- ❖ *It is believed that at least 1.5 million people in the U.S. have lupus.*
- ❖ *More than 16,000 new cases of lupus in the U.S. are reported each year.*
- ❖ *Lupus strikes mostly women of childbearing age.*
- ❖ *Women of color are 2-3 times more likely to develop lupus.*
- ❖ *People of all races and ethnic groups can develop lupus.*

Forms of Lupus

Systemic lupus erythematosus is the most common form of lupus, and is what most people mean when they refer to "lupus." Systemic lupus can be mild or severe. Some of the more serious complications involving major organ systems are:

- ❖ *inflammation of the kidneys (lupus nephritis)*
- ❖ *an increase in blood pressure in the lungs (pulmonary hypertension)*
- ❖ *inflammation of the heart muscle (myocarditis)*
- ❖ *hardening of the arteries (coronary artery disease)*
- ❖ *inflammation of the nervous system and brain*
- ❖ *inflammation of the brain's blood vessels*

Cutaneous lupus erythematosus is limited to the skin. Although cutaneous lupus can cause many types of rashes and lesions (sores), the most common rash is raised, scaly and red, but not itchy; it is called a *discoid rash* because the areas of rash are shaped like disks, or circles.

Another common example of cutaneous lupus is a rash over the cheeks and across the bridge of the nose, known as the *butterfly rash*. Hair loss and changes in the pigment, or color, of the skin are also symptoms of cutaneous lupus.

Drug-induced lupus is a lupus-like disease caused by certain prescription drugs. The drugs most commonly connected with drug-induced lupus are hydralazine (used to treat high blood pressure or hypertension), procainamide (used to treat irregular heart rhythms), and isoniazid (used to treat tuberculosis). The lupus-like symptoms usually disappear within six months after these drugs are stopped.

Neonatal lupus is a rare condition that can affect infants of women who have lupus. At birth, the infant may have a skin rash, liver problems, or low blood cell counts, but all of these symptoms disappear completely after several months with no lasting effects. A very small percentage of infants with neonatal lupus may also have a serious heart defect; however, most infants of mothers with lupus are entirely healthy.



Another common example of cutaneous lupus is a rash over the cheeks and across the bridge of the nose, known as the butterfly rash.



Understanding LUPUS

Most people with lupus will be treated by a rheumatologist, who is a specialist in the diseases of joints and muscles.

What Are the Symptoms of Lupus?

Because lupus can affect so many different organs, a wide range of symptoms can occur. The most common symptoms of lupus, which are the same for females and males, are:

- ❖ extreme fatigue (tiredness)
- ❖ headaches
- ❖ painful or swollen joints
- ❖ anemia (low numbers of red blood cells)
- ❖ fever
- ❖ swelling (edema) in feet, legs, hands, and/or around the eyes
- ❖ pain in chest on deep breathing (pleurisy)

What I Need to Know About Lupus

- ❖ butterfly-shaped rash across cheeks and nose
- ❖ sun- or light-sensitivity (photosensitivity)
- ❖ hair loss
- ❖ blood-clotting problems
- ❖ fingers turning white and/or blue when cold (Raynaud's phenomenon)
- ❖ ulcers in mouth or nose

What Kinds of Doctors Treat Lupus?

Most people with lupus will be treated by a *rheumatologist*, who is a specialist in the diseases of joints and muscles. The rashes or lesions from cutaneous lupus require treatment from a *dermatologist*, a specialist in diseases that affect the skin (including the scalp and the mouth).

Because lupus can cause damage to any part of the body, other specialists may be necessary, such as a *nephrologist*, who specializes in kidney problems; a *cardiologist*, who specializes in heart problems; a *neurologist*, who specializes in problems that affect the brain and nervous system; or a *perinatologist*, who specializes in high-risk pregnancies.



The Lupus Foundation of America (LFA) is the nation's leading nonprofit voluntary health organization dedicated to finding the causes of and cure for lupus and providing support and services to all people affected by the disease. The LFA and its network of chapters pursue this mission through programs of research, education and advocacy. Contact the LFA or a chapter that serves your area to find out how you can become involved in our mission and how we can help you. For more information call 1-800-558-0121 or visit us online at www.lupus.org.

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Are you in the band? Join the Lupus Foundation of America (LFA) and Band Together for Lupus™ to raise awareness and educate others about the needs of people affected by lupus. We are asking that you show your support and commitment to the millions of people worldwide impacted by lupus and "band together" by wearing a purple lupus awareness wristband.

Together, we can show our support for those who are working to develop a full arsenal of new treatments, and highlight the need for safe, more tolerable, and effective medications. Most importantly, we can offer hope to the millions of people affected by the disease.

Here's how you can get involved and "band together."

- **Wear a wristband!** [You can buy them at the LFA store](#), or [from your local LFA chapter](#). Don't forget to share them with your friends and family.
- **Spread the word.** Ask your friends and family to join us and "[band together](#)" by [sending an e-card](#).
- **Pledge your commitment to "band together"** and show your support for the millions of people affected by the disease.
- **Sign up to be an e-advocate and make your voice heard.** [Become an e-advocate](#) and tell Congress there is a critical need for increased funding for sound lupus research and education programs.
- **Join the band by following us Facebook, Twitter, or MySpace.** Check out our regular announcements on [Facebook](#) or [MySpace](#) or follow us on [Twitter](#). Put an [LFA wristband Twibbon](#) on your [Twitter account](#).
- **Make a donation.** Please consider [making a tax-deductible contribution to help the LFA](#) support research, education, and support services that benefit the 1.5 million Americans living with lupus and their families.
- **"Band Together" with an LFA chapter.** Find out what [your local LFA chapter is doing as part of the "Band Together for Lupus" campaign](#).



Show Your Support! Someone You Know Has Lupus.

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ABOUT OUR CHAPTER

The Lupus Foundation of America, Alaska Chapter, Inc. was formed in July of 1986 as a nonprofit, nonsectarian, all volunteer organization. Our purpose is to provide knowledge and enlightenment through education, to provide a common bond of support for Lupus patients, their families and friends, promote professional and public awareness and assist financially in research to find a cause, cure and improved treatment for this often life threatening chronic disease.

We are affiliated with the Alaska Community Share and are eligible for funds through Combined Federal Campaign (CFC) and United Way Donor Option. We are the primary lupus organization in Alaska that provides patients and the medical community and the general public with updated information, education programs and referral services.

We donate books to libraries, have medical reference material available to health professionals, participate in Health Fairs, air radio and TV public service announcements, distribute information through many sources within Alaska, make presentations to various organizations and publish a quarterly newsletter. We provide information packets to all inquiries, make appropriate referrals, offer support services on an individual basis as needed (hospital visits, transportation for medication and doctors appointments, meals taken to those too ill to cook, etc).

Our chapter has four general meetings (educational in nature with a health professional as guest speaker) each year that cover a wide variety of lupus-related topics to benefit the lupus patient, family, friends and general public. We have over six hundred different items of material that are available free of charge at the meetings and through the mail.

Support group meetings are held monthly in Anchorage and the Matanuska Valley. Support group meetings are held in Juneau on a bi-monthly basis. Support group meetings are held via telephone for the Southern and Northern areas of the state.

We are the resource that provides insight and knowledge in coping with chronic illness. Lupus patients and their families no longer have to feel isolated and that no one understands. Health professionals are gaining a greater perspective of the patients' point of view and are receiving current updated medical information. Our efforts in public and professional education have lead to greater physician awareness which then in turn has generated earlier diagnosis and lessened patient trauma. (Diagnosis in the earlier, milder forms can often lengthen life span by bringing under control the inflammatory process that damages major organs).

ABOUT OUR CHAPTER

Our mission is to provide knowledge and enlightenment through education. Provide a common bond of support and understanding for patients and their families. Promote public and professional awareness of the disease. Encourage and promote research by providing financial assistance in the hope that a cause and a cure and improved treatment will be found.

Our chapter was started in 1985 by a group of 10 people. In July, 1986 the chapter was incorporated as the Anchorage Chapter and was changed to the Alaska Chapter as it's role grew to serving the entire state of Alaska. The chapter is governed by a volunteer board which is elected by the membership. Growth has continued from the 10 to over 400 members and from serving 50 to 60 people per year to serving between 3,000 to 5,000 per year. The Lupus Link newsletter has grown from a hand typed 5 pages distributed to 50 to a professionally produced 12 page newsletter distributed to 800. We still remain an all volunteer organization. Support is given to lupus patients and also fibromyalgia, raynauds, sjogren's, scleroderma, and those who are suffering without a diagnosis.

We are affiliated with Alaska Community Share and are eligible for funds through Combined Federal Campaign (CFC) and United Way Donor Option. Personal donations are a major source of funding along with fundraising events.

IF ONLY THEIR
beauty
COULD KILL
the beast



LUPUS
The Predator Within

LUPUS

The Predator Within

LUPUS, the disease, has much in common with LUPUS, the Latin word for "wolf," for which it is named. Both are powerful, fierce, cunning, deceptive. Quiet one minute—and howling the next.

Although Robyne, Preston and Pamela—all living with lupus—appear healthy, they know the ravages of this predatory disease. As a wolf finds shelter in its lair, so too does lupus find shelter in their bodies, living out periods of active disease ("flares") and inactive disease ("remissions").

Lupus is a chronic inflammatory disease of the immune system. This system normally fights disease-causing invaders such as bacteria, viruses and cancers. But in lupus, the immune system attacks the patient's own tissues and organs. Lupus is the classic example of the immune system attacking its own body.

While the wolf has appeared on the endangered species list, lupus has not. There is no known cause. There is no known cure. It is nine times more prevalent in women than in men. African-Americans, Latinos, Asians and Native Americans are at greater risk than other populations.

CONSULT YOUR DOCTOR if you have three or more of the following symptoms on a regular basis:

- extreme fatigue
- joint pain
- persistent low-grade fever
- muscle ache
- facial rash
- pain in chest on deep breathing
- weight loss
- hair loss
- sensitivity to the sun
- mouth or nose ulcers
- seizures

The Lupus Foundation of America, Alaska Chapter serves all individuals with lupus, their families, their friends, the medical community and the public through educational programs, support services and research funding.

FOR ADDITIONAL INFORMATION, WRITE OR CALL

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