

LANtern® (Lupus Asian Network) 红斑狼疮之曙光 Bringing Lupus into the Asian American Limelight

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WHAT IS LUPUS & WHY IS IT IMPORTANT FOR ASIANS?

SLE Facts

- ▶ Systemic lupus erythematosus (SLE or "lupus") is a chronic autoimmune disease that can affect many parts of the body, including the skin, joints, bones, kidneys, lungs, central nervous system, heart, and blood.
- ▶ Lupus primarily affects women between the ages of 15-44.
- ▶ The disease manifests differently in each person, but common symptoms can include: joint pain or swelling, skin rashes, fever, weight loss, fatigue, hair loss, and sun sensitivity.
- ▶ The cause of lupus is unknown.
- ▶ There is no one test for lupus. Diagnosis is often difficult and involves a combination of laboratory and physical criteria.
- ▶ There is no cure for lupus, but treatment can include: use of steroids, anti-malarials, and chemotoxic agents.

SLE in Asians

- ▶ The prevalence rate is 2-3x higher for Asians than Caucasians. (multiple studies)
- ▶ There is a higher incidence of renal, neurologic disease, & major organ involvement over time. (Thomboo et al, 2001)
- ▶ Mortality rates are higher in Asians compared to whites. (Kaslow, 1982)

CULTURAL CHALLENGES

- ▶ Common misconceptions about the disease: Lupus is contagious. Lupus is a skin disease. Lupus is hereditary. Lupus is always fatal.
- ▶ Lack of recognition of physical symptoms because of elusive nature of symptoms and reluctance to complain
- ▶ Preference for the use of traditional treatment methods and Chinese medicine
- ▶ Language and communication barriers with healthcare providers can hinder optimal treatment
- ▶ Shame and stigma surrounding illness combined with strong sense of family privacy
- ▶ Reluctance to seek help for mental health concerns

A STRATEGIC RESPONSE: LANtern (Lupus Asian Network)

LANtern Mission

The mission of LANtern (Lupus Asian Network) is to support, empower, and enhance the quality of life of Asian-Americans with lupus and their families by creating networks of hope and understanding.

LANtern Goals

- ▶ Provide culturally sensitive and language appropriate peer health education to Asian-Americans and their families
- ▶ Empower Asian-American volunteers with lupus by training them as peer health educators and counselors
- ▶ Enhance access, communication, and understanding among relevant health providers, patients, and community resources to improve knowledge and support regarding the impact of lupus in Asian-American communities.

REACHING THE COMMUNITY THROUGH COLLABORATION

LANtern Advisory Board

- ▶ Our Advisory Board consists of physicians, peer consumers, and representatives from the following organizations:
S.L.E. Lupus Foundation, Inc., Charles B. Wang Community Health Center, New York Downtown Chinese Community Partnership for Health, Hospital for Joint Diseases, The Center for the Study of Asian American Health at NYU School of Medicine.
- ◆ First Advisory Board meeting in Dec.2001
- ◆ Quarterly meetings, chaired by the Program Coordinator, provide strategic direction and help inform priorities for the program.



BRIDGING THE LANGUAGE & CULTURAL DIVIDE THROUGH EDUCATIONAL PRINT MATERIALS

Publication in 2003 of 20-page bilingual booklet "What Chinese-Americans and Their Families Should Know About Lupus"

- ▶ First of its kind in the United States
 - ▶ Winner of two media awards for health communications: RxClub (2003) and The Communicator (2004)
 - ▶ Over 3000 booklets distributed across the U.S. and internationally
- Publication in 2006 of bilingual "Lupus: Myths & Facts" and "Talking About Lupus" brochures



These educational resources take into account health literacy levels and incorporate culturally relevant issues. Key points include:

- ▶ Encouraging open dialogue with MD, particularly about the use of Chinese medicine
- ▶ Reassuring that pregnancies can be successful
- ▶ Encouraging family communication, understanding, and support
- ▶ Decreasing the shame associated with living with a chronic illness

CREATING CONNECTIONS THROUGH THE PEER HEALTH EDUCATOR MODEL

LANtern Training

The use of peers in health education has been demonstrated to be culturally appropriate, effective, and powerful. The importance of the peer concept in Asian communities is even more relevant in helping to overcome the language barrier, taking advantage of word-of-mouth, and tackling concerns with confidentiality and privacy issues. Our LANtern Peer Health Educator volunteer training is a 6-week comprehensive and culturally relevant training.

Curriculum includes:

- ▶ Session 1: Overview of Lupus
- ▶ Session 2: Eastern & Western Approaches to Treating Lupus
- ▶ Session 3: Mental Health & Asians: Coping with Lupus
- ▶ Session 4 & 5: Peer Health Educator Skills: Cross-cultural communication issues
- ▶ Session 6: Accessing Resources

LANtern Support Line

- ▶ National toll-free number 866-505-2253, launched in April 2003
- ▶ Volunteers are available to speak to callers in Cantonese and Mandarin
- ▶ 498 Client contacts made
- ▶ Language breakdown: 44% Cantonese, 25% Mandarin, 30% English
- ▶ Category of callers: 34% Lupus patients, 33% family member/friend of person with lupus, 16% unsure if they or family member has lupus, 17% other
- ▶ Geographic origin: 65% Local (Tri-state area), 16% National, 4% International

Our peer volunteers have expressed feeling empowered by their ability to educate and learn from their clients and make a difference in their communities.

- ▶ *Forming a special bond:* "Because we speak the same language, they feel like you are very close to them." "She said 'I like when you call because it's like calling a friend.'"
- ▶ *Reciprocal relationship:* "Sometimes I learn from other patients when I call and then we share the experiences."
- ▶ *Providing a vehicle for discussion:* "I wouldn't go to a health fair and talk to people without LANtern. I only talk to my family and close friends, but to talk to people outside my circle and tell them that I have lupus is big."
- ▶ *Making a difference:* "That's the purpose why I joined the program. Because I want people to know about lupus...Why do we read the newspapers? Why we do the health fairs? That's the purpose. To let more people aware of the disease."

FOCUSING ATTENTION ON LUPUS AS A HEALTH ISSUE IN THE ASIAN COMMUNITY

- ▶ Educational presentations:
 - ◆ Medical staff
 - ◆ Health professionals
 - ◆ In-service trainings
- ▶ Local community outreach
 - ◆ Health fairs
 - ◆ Community events & conferences
 - ◆ Meet & Greet dinner event
- ▶ National outreach
 - ◆ Lupus conferences
 - ◆ Asian American conferences
 - ◆ Community organizations
- ▶ Media outreach
 - ◆ Ethnic print media – articles in Chinese newspapers
 - ◆ Radio campaign
 - ◆ Community information mailing
 - ◆ Asian American resource directories
 - ◆ Internet linkages
 - ◆ Cable television news story during Asian American Heritage Month



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