



*Unlocking the Mystery
of Lupus for Native
Women*

Final Report, September 2007

*Purchase Order
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Highlights

- During our recruitment campaign, we visited staff at 10 American Indian community agencies that reach hundreds of Native women, and shared information about Lupus and the seminars. Each agency received brochures and posters to distribute to clients. We provided pre-stamped, pre-addressed postcards for staff to give their clients to make registration easier. Twenty two individuals used this method for registration. To help recruit, we also staffed a booth at two major cultural events: a St. Paul powwow and the annual Indian Wellness Fair.
- We received in-kind support from four American Indian community agencies who allowed us to use their space and equipment, and helped us recruit women to attend the events. We also received in-kind support of prizes worth hundreds of dollars from the Lupus Foundation of MN, and a \$50 donation from the local Target store.
- Paid ads in the Circle News, a major Indian newspaper, and non-paid advertisements with our wolf logo announcing the event reached thousands of individuals. As we continued recruitment activities, and positive word-of-mouth spread through the community, participation in the seminars grew steadily over time, with full registration (20) and “over” registration (25) for the last 2 events in May.
- We reached 72 community women with our 4 sessions, and received high marks for satisfaction with the educational opportunity.
- Eighty percent of participants stated that they their understanding of Lupus “increased a lot” because of the session. For all of the knowledge items, we found statistically significant increases between pre and post-testing.
- We worked with staff at the two major Indian clinics that provide thousands of patient visits to Indian people in Minneapolis/St. Paul. We shared continuing education CDs on Lupus for health care providers, and brochures and promotional items for patients.
- We developed a strong ongoing relationship with the Lupus Foundation of MN (LFMN), who until this project, had conducted very limited outreach to Native communities. For the first time, they are actively inviting Native agencies to participate in their Lupus Walk in September. We educated the LFMN on cultural issues and epidemiology about the high rates of Lupus among Native people.
- The LFMN highlighted our work in the summer issue of their newsletter. Ms. Scott wrote the article, addressing cultural issues to raise awareness among LFMN members.
- We collaborated with the Lupus Foundation to conduct a special training which prepared four Indian women to be Community Health Leaders on Lupus. The group is diverse, with two of the four women themselves having Lupus.
- We attended the Living Strong wellness conference sponsored by the Mdewankanton Dakota tribe in July. Our popular booth with the Lupus Foundation was visited by hundreds of people from numerous tribes; we gave away almost all of our educational materials. Team member Maria McCoy served as a plenary speaker.



Seminars

During April and May, the collaborative team of Scott Consulting, Lupus Foundation of Minnesota and staff from the American Indian Family Center, Division of Indian Work and Indian Health Board completed four “Unlocking the Mysteries of Lupus for Native Women” seminars. The four-hour interactive, “lunch & learn” sessions followed the Office of Women’s Health format, and reached 72 urban American Indian community members with holistic information about Lupus. The seminars also raised awareness of American Indian issues among the three rheumatologists and staff of the Lupus Foundation of Minnesota.

Table 1. Dates and Sites for Lupus “Lunch and Learn” Sessions

Date	Site	Description	Attendees
April 14	American Indian Family Center	A “one-stop” shop for services for urban American Indians, including pre and post natal care, case management, financial and legal services and youth prevention.	12 (At least 2 people living with lupus, and several with family members having lupus or rheumatoid conditions)
April 28	Division of Indian Work	Provides social services, including parenting classes for pregnant teens, food shelf that serves over 20,000 people per year, family violence services and youth leadership and mentoring programs.	15 (At least 3 people living with Lupus, and several with family members having lupus or rheumatoid conditions)
May 12	Elders Lodge	A special housing project for American Indian elders.	20 (1 person living with lupus, 1 person being diagnosed and at least half with family members)
May 19	Minnesota Indian Women’s Resource Center	Provides residential and rehabilitation services for women struggling with substance abuse and family preservation issues, along with “cherish the children” childhood education center, an extensive library/clearinghouse on Native issues and support for Native women victims of sexual abuse.	25 (6 persons living with lupus or parent of child with lupus, 2 people “in process” with an unclear diagnosis)

We had an impressive group of speakers for the events, with attention paid to information provision, but also opportunity for interaction and sharing. The speakers included:

- Rheumatologists: Dr. John Schousboe, practicing MD and health researcher at the Park Nicollet Medical Center, Dr. Barb Segal, Professor and practicing MD from the University of MN (UMN), and Dr. Ali Sajjad, Rheumatology fellow at the UMN.
- Maria McCoy, American Indian woman living with lupus, who shared her personal story and opened the event with a sage purification ceremony
- Martha Eaves, attorney for Southern Minnesota Regional Legal Services and specialist in working with low-income people to receive needed social security and other services
- Gustavo Taberna, Outreach coordinator for the Lupus Foundation of MN, speaking about social services available for people with lupus and their families



- Timberly Williams, Client Services Manager for the Lupus Foundation of MN, speaking about social services available for people with lupus and their families
- Jessica Gorneau, PhD, Indian psychologist who spoke on historical trauma and coping with chronic illness
- Cheryl Secola, an American Indian wellness educator, who spoke on American Indian healing traditions and provided a cultural based closing
- Sheryl Scott, MPH, facilitated the events and provided background on the epidemiology and latest research on lupus in Indian communities



(l to r) Sheryl Scott, Martha Eaves, Maria McCoy, Cheryl Secola, Dr. Jessica Gourneau, Gustavo Taberna

During the event, we provided opportunities for discussion and Q&A with the experts. Each participant received a formal packet that included a list of key community resources, brochures from the Lupus Foundation, a copy of the *Many Shades of Lupus* brochure and the application form for the Native American Lupus

Registry. We held drawings for prizes throughout the event (sun protective hats, mugs, travel blankets and t-shirts from the Lupus Foundation) and shared giveaways at the closing including a gift card and herbal cedar soaps made by local Ojibwe women.

Special Note on Lupus Registries. During our project, we found that Indian people were not aware of the Lupus Registry and confused it with being in a “study at the University”. However, we also felt that individuals were open to learning about the Registry and were pleased that someone was paying attention to including the Indian community. We placed the brochure about the Native registry in all of our seminar packets and encouraged people to pass along the information to join, with the message that it was “about finding a cure that would work for our people”. Our team believes that our best role is to *raise awareness* rather than “sign people up”.

In general, we were disappointed that the Registry we contacted had such limited resources, and could not follow up our request to include a speaker on their Registry work. They did not even have a video to show, or a good brochure. We were happy to share the brochure they sent but frustrated that it was so poorly designed (very high literacy level) and that we had to make several requests to get actual copies (rather than just the email copy they originally sent.)

Our recommendation for the future would be to *provide funds for a specific, focused project to work with Lupus Registries and community agencies* to develop culturally-appropriate recruitment materials and messages (e.g., video with personal stories would be effective for our community.) We had a good discussion with a woman who had participated in the Registry with her daughter. She would be very open to doing a video to share their family experience with the Registry to get the word out to others in the Indian community.



Recruitment and Community Awareness Building

The community planning team created a recruitment plan that serves two goals: advertise the Lunch & Learn sessions, and also build awareness about lupus among American Indians within the strong network of community services for American Indian people. We used three strategies, including brochures (Appendix 1), personal “recruiting” visits and paid ads in the *Circle News*, which is the major Minnesota American Indian monthly newspaper.

Paid Advertisements. We placed paid advertisements in the *Circle News* during the months of April and May (Box 1). The ad was well placed, and we received many registration calls from this strategy. We are also pleased to be able to support the local Indian press. We encouraged the Lupus Foundation to continue this support by advertising their events in the local Indian press.

Recruiting Visits. Overall, our 10 recruiting visits were productive, and through these visits, we reached many more people than we would have if we had just used print media. Agencies included:

- Minnesota Indian Women’s Resource Center
- St. Paul Indian Education
- Indigenous Peoples Task Force
- American Indian Family Center
- Ain Dah Yung
- American Indian Annual Wellness event
- St. Paul Indian Education Year End Powow Celebration
- Native American Community Clinic
- Division of Indian Work
- Indian Health Board

Staff from community agencies expressed great interest in this topic, and brochures and educational information were well-received. Even if the staff did not attend the seminar, we felt that basics about Lupus reached key staff people in the community. We also provided the staff with pre-addressed, pre-stamped registration postcards to share with their clients to encourage participation. We found that the advertisement in the local American Indian newspaper generated a good deal of interest from community members. The toll free number was an essential element of helping make the registration process easy and effective.

The annual American Indian Wellness event at the American Indian Center in April was a very important awareness builder for the community. The event is attended by hundreds of community members throughout the metropolitan area.

Box 1. Paid Ad in the Circle News



Do you or someone you know have Lupus, the disease named after the wolf?

Come have lunch at one of our *FREE* sessions to learn about services to help. You will hear from:

- *Medical expert
- *Disability attorney
- *Native psychologist
- *Lupus Foundation
- *Traditional educator

You will also hear Maria’s story, a Native woman with Lupus, who is living well after struggling for years.

April 14, AIFC, St Paul
April 28th, DIW, Mpls
May 12, AIFC, St Paul
May 19, MIWRC, Mpls

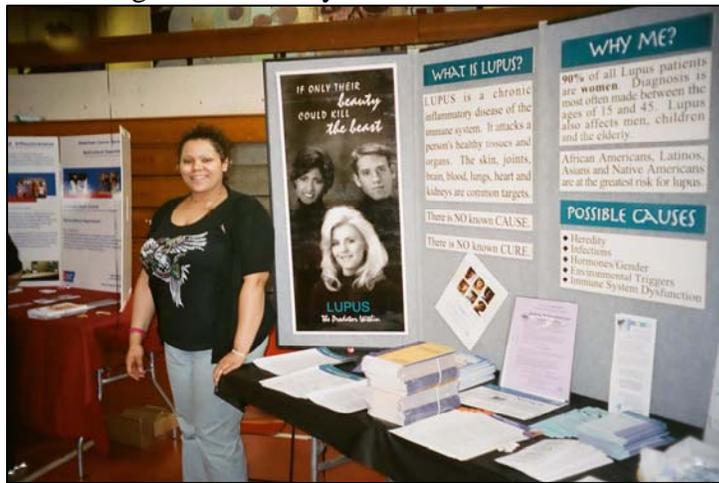
Receive a \$20 Target card if you pre-register!
(limit one per person)

Call 1-866-374-8313



Dozens of individuals stopped by the booth to ask about Lupus, or to share stories of their loved ones who have or are suffering from the condition. We distributed all of our brochures and copies of the NIH pamphlets on Lupus. We used the opportunity to sign up individuals to attend the upcoming seminars, and registered five new attendees. The booth also gave us a chance to reinforce our message with staff of community agencies, several of whom stopped by to say hello after having met us at the Lupus recruiting staff presentations. In the eyes of community members, our presence at this important community event solidified our commitment to reach the Indian community with information about this critical health condition.

In addition, two Lupus Foundation staff, who had not previously attended an Indian event, learned a great deal. They had a chance to visit the other booths and meet staff from community agencies that provide services to thousands of Indian people in our area.



Lina Wade, Lupus Foundation, helps staff booth at the Indian Wellness event.

We also provided a booth at the St. Paul Indian Education powwow in late April. This is an important community gathering, especially as it was the end of the school year event. We talked to community members, as well as community leaders, and shared brochures and giveaways, also distributing our recruitment materials for the seminars.

Community Health Leader for Lupus Program

On April 12th, Community Health Leaders for Lupus (CHLLs) received training from Timberly Williams, a seasoned trainer from the Lupus Foundation of Minnesota.

Maria McCoy – Maria (Turtle Mountain Ojibwe) is a wonderful role model for Native women living with Lupus. Maria struggled for many years, but now is symptom free. She shares her story of living in balance, being “proactive” and taking care of self. She is women’s health case manager at the American Indian Family Center.

Shellie Little Dog – Shellie (Ojibwe) is an educator who serves many clients as a staff member of the Diabetes program at the Indian Health Board of Minneapolis. She is interested in working with Indian Health Board staff and with community members to increase their awareness and understanding of Lupus.

Suzanne Tibbetts Young – Suzanne (Ojibwe) is Director of Adult Services at the Division of Indian Work, which includes the Food Shelf, diabetes prevention and family violence programs. She has an MA in education from St. Mary’s University, and is a leader in building programs to help empower Indian families within the Twin Cities.

Andrea Law – Andrea (Winnebago/Cree) is a young woman who also participated as a member of our community planning team. She is a student at a local community college, and is interested in reaching younger Native women with important health messages.



Timberly Williams, long term survivor of Lupus and certified trainer for the Lupus Foundation of MN, provided a morning full of insight and training on how to reach community members through education. We provided specialized bags of community education materials to the CHLLs for use in their outreach education, and developed evaluation forms to collect information about their activities. The group is diverse, with two of the four American Indian women themselves having Lupus. Three of the women work in community agencies, and one is a young community college student. Two are from Minneapolis and two from St. Paul.



CHLL Accomplishments.

All of the CHLLs completed a post-training questionnaire demonstrating their knowledge about Lupus before beginning their community education. By the end of August, three of the CHLLs had completed 6 educational sessions, with the fourth CHLL scheduled to conduct 2 sessions in September. They had reached 36 staff members of key Indian agencies and 17 community women.

Highlights of the educational sessions include:

- *Division of Indian Work Family Violence Program*– A one-hour session attended by 8 staff, primarily younger adults aged 23 to 44. Pre and post-tests showed acquisition of important new information. For example, before the session, no one named “rheumatologist” as the specialist to see for Lupus, only one person was aware of the Lupus Foundation and only two knew that the disease was most common among women aged 15 to 45. After the session, all were able to correctly answer those questions.
- *Horizons Unlimited Program* – This 90 minute session reached 12 staff, volunteers and interns for the food shelf and diabetes prevention program. Qualitative evaluation showed that staff enjoyed the session and learned key facts about Lupus for Native people and ways to support those with Lupus. They also shared ideas for future educational efforts.
- *American Indian Family Center Staff Meeting* – This 15 minute awareness-raising session for 16 staff members of this key community agency focused on basic Lupus facts and the importance of getting information to the Indian community. Staff showed a very high interest in learning and would like to see more data on the causes and effects of Lupus in Indian tribes. They shared ideas for new projects, which included doing work with colleges.
- *Crossroads Elementary Early Childhood Family Education Class* – This session provided basic Lupus education to 9 Indian young mothers aged 17 to 37 in an early childhood education class.



- *Mothers Circle* – This 20 minute session for 8 mothers of young children took the form of a Talking Circle, which is an American Indian traditional way of gaining support and sharing information. The women were very interested in the information. Pre-tests showed that almost all of the women were unaware of basic facts, including symptoms, young age of onset, the need to see a rheumatologist and the Lupus Foundation. After the session, almost all of the women were familiar with symptoms and facts about the disease, and could name the Lupus Foundation of MN as the place to go for services.
- *Living Strong with Chronic Disease Conference* sponsored by the Shakopee Mdewakanton Sioux – One of the CHLLs staffed the booth at this important health conference attended by hundreds of Indian people from throughout the North, representing tribes from the Minnesota, Wisconsin, Michigan and the Dakotas. Another CHLL was a plenary speaker. This was an excellent opportunity to reach individuals and to build the confidence, skills and capacity of the young adult CHLL.

Other events:

The CHLLs plan to remain active as community educators, and the Lupus Foundation will continue to collaborate with them, and draw on their knowledge as they develop educational programs and support groups. They have become members and will receive all newsletters and benefits. The Lupus Foundation has also asked the CHLLs to attend their upcoming 10th Annual Lupus Walk and event.

Networking

A major accomplishment of this project has been networking, or what we would describe as serving as a bridge between our “two worlds”, that is, the Indian and non-Indian cultures. We educated non-Indians about cultural issues and helped them reach this under-served community, and we raised awareness within the Indian community about Lupus and the many services offered by the Lupus Foundation. Both groups seemed very ready for this opportunity.

Lupus Foundation of MN

We have created a strong partnership with Lupus Foundation of MN. The Foundation:

- Served on our planning team, advertised seminars on their website and distributed flyers;
- Provided the CHLL training; Timberly Williams, who has 20 years of experience training for the Lupus Foundation of MN, conducted the morning segment of the CHLL training;
- Donated educational and promotional materials worth hundreds of dollars for recruiting and education;
- Advertised our seminars in their quarterly newsletter and on their website (lupusmn.org);
- Conducted joint exhibits at the Indian Wellness event in April and the Living Strong conference in July;
- Included an article by Sheryl Scott with highlights of the *Unlocking the Mysteries for Native Women* and cultural issues in the Summer 2007 newsletter (Appendix 2);
- Began a recruitment campaign to insure that Indian agencies and community members participate in their 10th Annual Walk for Lupus in September. A prominent Indian women’s health leader has been invited to speak at the opening ceremony.





The staff of the Lupus Foundation expressed over and over again their appreciation to our project for its success in reaching American Indians, and providing information about the services of the Lupus Foundation. The staff learned a great deal about important cultural issues for Native people, for example:

- The Native view of the wolf as a positive force, playing a very important role in some tribes, rather than the sly or even evil connotation brought from European cultures. We had to replace several educational materials that were very negative about the wolf, and had good discussions with staff members about why this is important.
- The specific ways that the European invasion changed Indian culture and left them suffering from historical trauma, which was shared at all sessions by Dr. Jessica Gourneau as she discussed healthy coping for Native people living with Lupus.
- The holistic medicine wheel concept, which attends to the four directions of health -- physical, emotional, social/spiritual and mental-- not just the physical, as well as how Indian cultures stress the important role of women, ceremonies and spirituality for healing.

Reaching Urban Indians

A common misconception is the all American Indians have health care. Urban Indians have some of the worst health statistics in the U.S. Many urban Indians are not covered by Indian Health Services, are too poor to travel to the reservation to receive care or do not have access to specialists or appointments.

Thus, we are delighted to have the two major health care providers for urban Indians participating in our project. Annually, the Indian Health Board admits about 12,000 patients medically and about 60% are Native, while the Native American Community Clinic serves over 5,800 people with 40,000 patient visits and 85% are Native.

Urban Indian Health Providers

We have established relationships with the two major urban Indian health providers in the Twin Cities: The Minneapolis Indian Health Board (MIHB) and Native American Community Clinic (NACC). Shellie Little Dog, who was diagnosed with Lupus last year, is an educator at the MIHB and received training as a CHLL. She will provide an educational session for MIHB staff. The MIHB provides medical services to thousands of Indian patients every year.

Connie Norman, Health Promotion Coordinator from NACC was originally scheduled to receive CHLL training but could not participate due to family illness. However, we met individually to discuss how we might support educating their medical and adjunct staff about Lupus. She is very interested in this issue for personal (a relative was recently diagnosed) as well as professional reasons (she is a certified trainer for the Arthritis Foundation in living well with chronic illness). We discussed how we could be of assistance to her and to the staff at NACC. As a result, we provided educational materials for patients, a copy of the NIH CD-Rom on Lupus for Health Providers and a

copy of the CME presentation from Arizona for their health professionals to view as part of their staff updates. We also provided information to encourage their clients to participate in the national Lupus registry. NACC was very pleased to receive these materials.



Rheumatologists

We worked with three rheumatologists to deliver education information during our seminars. As part of the process of preparing them to speak at the seminars, we provided the rheumatologists with our literature review of epidemiologic studies on Lupus and arthritis in North American Indians (Appendix 3). All of the rheumatologists mentioned the data, but Dr. Schousboe in particular, was very interested in these statistics, and discussed them at length with the seminar participants. He was especially interested in the meaning of the disparities between tribes. As a health services researcher, he mentioned this was an important area for further study.

Shakopee Mdewakanton Sioux Tribal regional conference

We were invited by the Mdewakanton Sioux Tribal health program to participate in their “Living Strong” conference in July. The conference was over capacity, serving approximately 700 participants, the vast majority being American Indians from the Northern states. The free conference focused on education about chronic illness, and exhibit areas was very busy as participants were eager to learn about health issues for Indian people.

Maria McCoy, one of our Community Health Leaders for Lupus and a member of our core planning team, served as a plenary speaker at the conference, reaching all participants as she shared her story of learning to live in balance with Lupus, drawing on Indian strengths.

During Maria’s talk, we provided audience members with an easy-to-read bookmark from the Lupus Foundation which outlines the 10 common

symptoms of Lupus on one side, and provides basic facts about Lupus on the other. At the conference, Office of Women’s Health Project Officer Susan Russell Sanders joined Ms. Scott in presenting Maria with a certificate of achievement



Susan Sanders (Office of Women’s Health) and Sheryl Scott (Scott Consulting) thank Maria McCoy for her work as a Community Health Leader at the Mdewakanton Sioux “Living Strong” conference in July 2007

This was the first time a Lupus-related booth or speaker participated in the Mdewakanton conference. We encountered many individuals who said that had never heard of Lupus, but tragically, just as many who said they had a young relative or friend who had died of the disease. We gave out hundreds of copies of educational materials, bracelets, brochures, newsletters and bookmarks. For those individuals who shared that they or a family member had Lupus, we provided specially created packets of materials with additional detailed pamphlets from NIH.



Impact of Seminars on Participants and Community

Our evaluation plan consisted of using two methods to answer major evaluation questions on the impact of the seminars and CHLL program, as detailed below.

1) Did the seminars increase the knowledge, awareness and intentions of participants?

Methods:

Pre/post evaluation forms from all seminar participants

Follow-up telephone surveys with 10% of seminar participants

2) Were the participants satisfied with the seminars, and did they have ideas for improvement?

Methods:

Questions on the post-test evaluation

Follow-up telephone surveys with 10% of seminar participants

All seminar participants received an informed consent statement before completing their pre/post evaluation forms or follow-up survey. No identifying information was included on any of the forms. The Data Analyst entered data into a spreadsheet which was then imported into SPSS for statistical analysis. For the follow-up telephone survey, participants were asked for verbal consent. The Program Director conducted content analysis and summarized responses into major categories.

Results

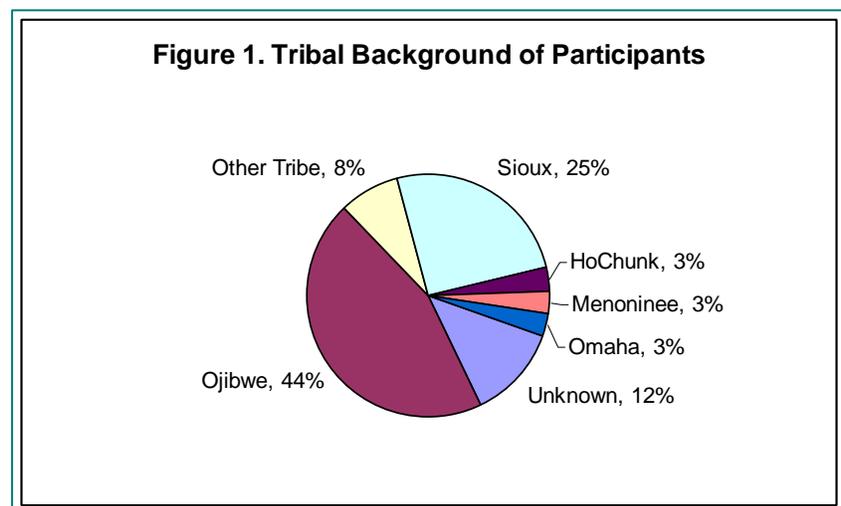
1) The *Unlocking the Mystery of Lupus* seminars increased the participants' knowledge and awareness regarding Lupus.

Pre/Post Survey

Demographics. We reached 72 community members as participants in our seminars, and received 62 paired pre and post tests, which represents 86% of participants. Figure 1 shows their tribal background, with Objibwe and Sioux being the most common tribes represented, as would be expected since these are the main tribes in Minnesota.

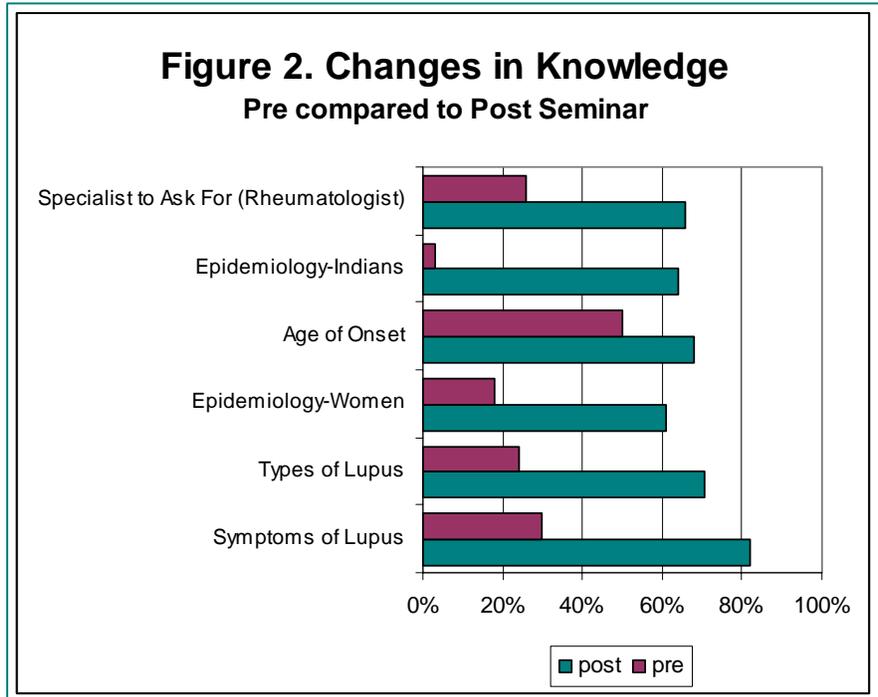
The HoChunk and

Menoninee are Wisconsin tribes, while the Omaha are in both Nebraska and Oklahoma. Other tribes included Cherokee and Sac and Fox. We also had three participants of Hispanic descent. All but two of participants were female, and the mean age was 45. Three teenagers attended and about 50% were in the age range with the highest prevalence of Lupus (under age 45).



Knowledge Gains. Eighty percent stated that their understanding of Lupus “increased a lot” because of the session. For all of the knowledge items, we found statistically significant increases between pre and post-testing. Increases varied by item, but key knowledge gains are shown in Figure 2.

We found gains in important concepts for awareness, such as the symptoms of Lupus and the higher rates among our Indian people (epidemiology question). Almost 50% of the participants were already aware that Lupus most commonly strikes women of child-bearing age, but less than one-third were knowledgeable about other aspects before the seminar.



When asked an open-ended question about what they would share with others, 30 participants took the time to share a response. They reported that they would share messages on:

- Symptoms of Lupus
- “Don’t wait” thinking it will go away, it is important to get medical attention
- Listen to your body and take care of yourself
- Native women need to become educated about diseases that affect them
- Go to future seminars to learn more about Lupus
- Understand what others go through with Lupus

Follow-up Interview

We interviewed seven participants spanning all four seminars. Participants remembered key messages several weeks after attending the seminar, specifically mentioning:

- We need to take care of ourselves, resting and reducing stress are important
- Watch for signs, especially tiredness
- Lupus attacks the organs & joints
- Lupus is hard to diagnose
- Natives have a higher rate of Lupus

The participants universally reported that the information was useful, and they appreciated hearing from a diversity of speakers. Several noted appreciation for having a rheumatologist attend. Several mentioned that the information about getting on SSI and disability was important to know, especially as they are in the process of being diagnosed. Others have gone to their doctor to be tested, bringing information from the seminars. All of the women interviewed had shared information with family members, primarily with their children or siblings.



2) The participants were satisfied with the seminars, and shared ideas for improvement.

Pre/Post Survey

At the end of the training, 43 participants shared “one thing you really like about today’s session”.

Many of the comments were generic, such as “everything”, “the speakers” or “all of it”. Seven people specifically mentioned the rheumatologist as a highlight, four people mentioned Maria (Native woman living with Lupus), three people mentioned healing traditions, three people said Native personal stories/voices, and two people each mentioned Timberly Williams and Gustavo of the Lupus Foundation. Other, more personal, comments included:

“Knowing I am not alone”

*“I can understand better when my friend talks about Lupus.
I am grateful to you for helping me understand Lupus.”*

Follow-up Interview

During the follow-up interview, we asked participants what they thought we should do next to help Indian people with Lupus, and also, to share ideas on what we should keep and what they would do differently if we did the seminars again.

Ideas. Two participants felt the seminars worked well as is: one said “perfect – very educational and well done”, while the other said “informative, don’t change anything”. However, she did go on to say that cell phones and talking during the seminars sometimes distracted her, so we should make sure to remind people to turn them off before we begin.

Others shared ideas such as continuing to work with the doctor to ensure their ability to participate – perhaps scheduling on a weekday instead of a Saturday for their convenience. Another felt that it was too long – however, she liked the diverse speakers but thought perhaps we could cut the time allotted for each presentation, rather than cut out specific speakers.

Next steps. We had some interesting ideas for next steps (besides holding more seminars). These included:

- **Offer support for people and caregivers with Lupus**, to help them feel comfortable asking for help and encourage use of counseling resources
“like when I had depression, I didn’t ask for help. That was hard on my family – it’s really important that they know what’s going on”
- **Educate clinics and doctors available to Indian people**, and make available doctors who know how to work with Indian people
“Get doctors to be more helpful – I feel not listened to and would like to have better doctors that could work with Indian people”



Summary and Recommendations

Challenges

Lack of Staff Time for Scope of Work. The project manager spent an additional 244 hours over what was budgeted for this project. Part of this was due to staff turnover (described below), but we estimate that the project would have required an additional 150 hours even without staff turnover. The effort needed to coordinate 4 seminars in low-resource communities is significant.

Recruiting Rheumatologists. Despite being in a major urban center with numerous universities, health systems and hospitals, we had a difficult time finding a specialist who would speak at our sessions. While the LFMN took the initial “responsibility” for finding a speaker, they had limited success, partially because they had already scheduled speakers for another event. It was a disappointment that the LFMN could not supply us with a speaker. Gustavo Taberna, our LFMN team member, who himself has Lupus, finally approached his own physician, who agreed to speak at the first session. We taped his presentation in case we did not find another speaker. Ms. Scott then spent many hours “cold calling” rheumatologists, and also contacted the OWH funded Centers for Excellence in Women’s Health at the University of Minnesota. Staff member Lauren Gilchrist helped us to recruit a medical expert in Lupus, Dr. Barb Segal. Dr. Segal helped us by personally asking her rheumatology fellows to serve as speakers. Unfortunately, for two of the sessions we didn’t know until two days before the event if the speaker would attend. This led to both frustration and extra work in preparing for the contingency of not having a rheumatologist.

Staff Illnesses and Turnover. We had some challenges due to staff turnover within one of our partnering agencies and within our own consulting staff. We lost consultant Jennifer Irving halfway through the project. While she was able to recruiting an excellent array of culturally-responsive speakers, she moved out-of-state to take a new job and could not serve as facilitator or community recruitment coordinator. Our other consultant, Andrea Law, was unable to continue to serve in her capacity as coordinator, so Ms. Scott stepped up to conduct more of this work. We also recruited Maria McCoy, a Native woman living with Lupus, who was able to assist with some of the facilitation and recruiting activities.

We were also hit by the sudden hospitalization of our Lupus Foundation partner just after the first seminar. Gustavo suffered kidney problems from his Lupus, and was unable to assist and attend during the second two seminars. We were very concerned about his health, and pleased to have him return for the last seminar. This loss of support, however, did present a challenge in terms of both worry about his health, plus an extra workload, for the project manager.

Exclusion of American Indians. The lack of research and culturally relevant materials for the Indian community continues to be a major challenge. We found very few studies on Lupus and only one handout that had been developed specifically for Native people. While we were grateful that the handout was provided free-of-charge by the national Lupus Foundation, the content and graphics were not very appealing or culturally responsive. In addition, we reviewed dozens of websites, some outstanding with excellent media streams of video stories from individuals living with or loving someone with Lupus. But we could find none that included stories from Native women. (A good example is dxlupus.org).





We also noted that the advocacy work being done by national Lupus organizations for increasing funding for projects through the Defense Department (shared as information only during the project), did not include mention of American Indians, despite epidemiology that suggests some tribes have the highest rates in the United States. We also contacted the National Native American Lupus Registry, but found they had no speakers available, or recruitment videos that were tailored to or reflective of our community. We seem to be consistently invisible on the national “radar screen” of major Lupus education and research groups.

Recommendations

Additional funds or reduced scope of work. We would recommend increasing funds, or reducing the scope of work to one “big event” seminar within the same budget parameters.

Assistance with recruiting rheumatologists. Our difficulties in recruiting rheumatologists may have been overcome by establishing a relationship with the OWH funded programs (e.g., the Centers for Excellence). We would suggest that the OWH require their Center for Excellence projects to partner with the Lupus projects to help them in this area.

Reaching tribal members in reservation settings. Our recommendation for future projects would be to focus on tribal sites, as well as urban. Because the urban community in Minnesota is so large, we believe that having four sessions was a good choice for the current project. However, reaching the reservations, especially in Northern Minnesota, the Dakotas and Wisconsin, where medical care is less available, would be a natural and effective next step.

Education for Health Providers. Seminar participants suggested educational events to build awareness, knowledge and skills for health providers working with Indian communities.

Flexibility in formatting. After conducting four seminars, we recommend a different strategy for our smaller population. The major effort to put on four different seminars (given that we had to find a different rheumatologist each time, plus substitutes for other speakers who couldn’t make all the dates) could have been better spent. We believe that it may have been more effective to put funds, time and effort into recruiting and awareness-raising efforts, followed by one large seminar event. Personal visits to American Indian community agency staff meetings were very fruitful and allowed for excellent discussion about the topic of Lupus and how agencies could help serve as bridge to identify women at risk and get them to medical care. We could have done more of these meetings, generating interest and motivation for women to attend a larger seminar, with more funds going to one seminar program with a community feast and/or Powwow.

Summary

The Office of Women’s Health provided us with a wonderful opportunity to learn more about Lupus for American Indian women, and to reach this population which is so underserved. Women at our seminars were grateful for the chance to share their thoughts, to listen and to learn.

“There’s a lot of stuff we don’t know, but with the help of others, we can learn more about it. I will tell others how vitally important the lupus sessions are.”

April 28 seminar participant



Appendix One:

Lupus Awareness
Building &
Recruitment
Brochure



Lupus is the Latin name for wolf. Before the days of drug treatment, the disease caused rashes that looked like wolf bites.

Lupus is a disease that has many symptoms, such as joint pain, fever, tiredness, skin rashes, blood and kidney problems. It can be very painful. Without attention, it can cause organ failure, and even death.

Lupus is more common in the Native community, so learn how to help our people who are living with this disease. Join us for a free "lunch and learn" session!

Limited to 25 people so CALL 1-866-374-8313 or email sherscott@earthlink.net to reserve a space (lunch & gift)!

ALL SESSIONS WILL BE HANDICAPPED ACCESSIBLE. CALL IF YOU NEED SIGN LANGUAGE AVAILABLE!

Funding provided by the Office of Women's Health

Sponsored by Scott Consulting and the Lupus Foundation of MN



Unlocking the Mystery of Lupus for Native Women



a series of free seminars to raise awareness on living well with lupus

Problem:

American Indians, especially women between the ages of 18 and 45, get Lupus more than other people.

Solution:

 *You can live well with lupus!* Find out if you have it early - and then take good care of yourself by getting proper medical care and support from the community.

Problem:

There is no cure (*yet*), and not much is known about Lupus in American Indians.

Solution:

 You can get treatment for symptoms that makes lupus easier to manage. There is also real promise and hope for a cure! Visit your doctor regularly, and go to your traditional healer if you use one. If you *do* have lupus, you can **be a part of a special study**, called a "clinical trial".

We still have many questions about lupus but you can help! If you or a family member has Lupus, **you can enroll in a Lupus Registry**. This is a study that looks at the blood of many people from all walks of life to find a cure. But few American Indians have joined, so we need our people to help.

Problem:

American Indians don't get information about Lupus.

Solution:

 Come to one of our seminars to learn more! We will be holding free "lunch and learn" sessions so you can find out more about Lupus, cultural healing for our community and services available in Minneapolis and St. Paul.

Schedule

All seminars from 12 to 4pm

Saturday, April 28 FILLED!

Minneapolis

Division of Indian Work

Saturday, May 12

St. Paul

Elders Lodge

1500 Magnolia Avenue

Saturday, May 19

Minneapolis

MN Indian Women's Resource Ctr

Space is limited to 25 people per FREE event. Call 1-866-374-8313 toll free or email sherscott@earthlink.net to reserve your lunch and gift (includes \$20 Target card)



Appendix Two:

Lupus Foundation of MN Newsletter Article Summer 2007

(available at Lupusmn.org)

Unlocking the Mysteries of Lupus for Native Women

By Sheryl Scott, MPH

"Lupus coming into my life brought about a major shift in my lifestyle," says Maria McCoy, a Turtle Mountain Ojibwe woman living with lupus for over a decade. "I had to take a hard look at myself and found that I was out of balance. I was in an unhealthy relationship, living under a lot of stress and not doing the basic things every person should do to live a healthy lifestyle. The changes I have made brought transformation for me in so many ways. I now am living well with lupus."

Northern Tribes Suffer High Rates of Lupus

Maria's is one of many untold stories of Native American women who are living with lupus. Unfortunately, very little research has been conducted on how many Native women suffer from this condition, and little attention has been paid to how lupus impacts this community. But because of a recent project funded by federal Office of Women's Health, the Twin Cities community has had the opportunity to learn more. "When we looked at the few scientific articles that had been published, we were alarmed at the disparities suffered by Native people in the United States and Canada," reports Sheryl Scott, MPH, and project coordinator. "Especially that tribes in our area show rates 3 to 15 times higher than expected, along with poorer outcomes. Distressingly, Native children are at higher risk. We knew we needed to do something to reach community members with important information on this disease."

Drawing On Cultural Strengths

American Indian tribes have unique cultural backgrounds which need to be addressed when developing health education, prevention and treatment. A good example is in the very name of the disease: Lupus is the Latin name for wolf, an animal feared and even considered evil in European cultures. In stark contrast, many tribes hold the wolf in high esteem, recognizing its power and admiring its ability to survive in the natural world. The wolf is a central figure in teaching stories and lessons for many tribes.

Keeping such issues in mind, a team of community members, including Ms. Scott and Andrea Law of Scott Consulting, Jennifer Irving and Maria McCoy of the American Indian Family Center, and Gustavo Taberna of the Lupus Foundation of Minnesota, worked throughout the spring of 2007 to plan and implement four educational sessions that would take into account the culture of Native women. The team used the successful OWH "Unlocking the Mysteries of Lupus" model, which fits well with Native culture given its emphasis on a holistic approach. Many tribal communities draw on a holistic circle or "Medicine Wheel" encompassing spiritual, social, mental and emotional components of being. Addressing these areas, the sessions included a Native psychologist (Dr. Jessica Gorneau of the American Indian Family Center), a disability attorney with 30 years of experience (Martha Eaves, Southern Minnesota Regional Legal Services), a Native woman living with lupus (Maria McCoy, American Indian Family Center) an educator on traditional Native healing (Cheryl Secola, Indian Health Board and Division of Indian Work), and a speaker on social services available to people living with lupus (Gustavo Taberna, Lupus Foundation of Minnesota).

Participants heard about the medical aspects of lupus from area rheumatologists (Dr. John Schoushoe, Dr. Barb Segal and Dr. Ali Sajjad), the wonderful array of social services available from staff of the Lupus Foundation of Minnesota, and practical tips on how to navigate the confusing paper maze to receive disability from attorney Martha Eaves (which one participant dubbed "nuggets of gold"). Three Native women from the Twin Cities served as cultural anchors for the sessions. Maria McCoy led the group in an opening with a sage purification, then shared her personal story and invited the group to share their question. Psychologist Dr. Gorneau, (Turtle Mountain) outlined the terrible price of historical trauma among Indian people, but yet used humor (an Indian strength!) and personal stories to remind participants about their positive assets and ways of coping that have helped Indian people survive, and even thrive. Cheryl Secola (Bois Forte Ojibwe) ended the session by speaking from the heart about the importance and strength of connecting with tribal traditions, and drawing on the knowledge of elders.

Next Steps

"Many people are misinformed about American Indians and health care," emphasizes Sheryl Scott. "They just think 'oh, the government takes care of them, or the casino pays for it'. Well the truth is far different. The Indian Health Service, the government body responsible for health care for American Indians, is woefully under-funded and very often provides no access to specialists. During the mid-1900s, the U.S. government tried to assimilate Indian people by moving them to urban areas, and those individuals now have to struggle for access to health care as they are away from their reservation or are not officially enrolled." The good news is that some tribes are gaining ground economically, and for people enrolled in those tribes, health services are getting better. The challenge is to reach those who are unaware and continue to suffer without access to health care or the social services provided specifically for people with lupus by places such as the Lupus Foundation.

Gustavo Taberna, outreach specialist for the Lupus Foundation, is committed to continue this work with Native communities. In mid-July, the team will share an exhibit at the Living Strong conference sponsored by the Mdewakanton Sioux (Dakota). The free conference is one of the largest health events specifically for Native people in the region; 700 people participated in 2006. The community team has been invited to speak by conference organizers, and Maria McCoy will do the honors.

"We are here to help and be of service to others," Maria remarks. "But in order to live in balance we must take good care of ourselves as women and Indian people, and this is a gift not only to ourselves but to our community. I have learned this lesson in my experience living with lupus."

* Note: The terms *American Indian*, *Native American* and *Native* are all commonly used terms for this community.

Appendix Three:

References for Lupus Epidemiology in Native communities

Summary of Research on Epidemiology of Lupus in Native Populations

- **Lupus was 2 to 3 times higher among American Indian adults and children in searches of arthritis databases and medical records of specialists. (1, 2)**
- **Lupus was found among younger ages and caused more damage and mortality. (1, 3)**
- **In American Indians, a family history of autoimmunity or arthritic disease is more common. (2, 3)**
- **Other rheumatic disease is more common, with arthritis very high among children in the Billings IHS Area. (3, 4)**
- **A review of IHS records showed high disparities (3 to 15 times higher) in several IHS areas, including those with tribes most common in the Twin Cities: Bemidji and Aberdeen. (5)**

1. Systemic lupus erythematosus in North American Indians: a population based study.

J Rheumatol. 2000 Aug;27(8):1884-91. Peschken CA, Esdaile JM.

OBJECTIVE: To evaluate the prevalence, disease course, and survival of patients with systemic lupus erythematosus (SLE) in a population of over 120,000 North American Indians (NAI), and contrast the results to those in the non-Indian population. **METHODS:** The regional arthritis center database and the medical records of all rheumatologists, hematologists, nephrologists, and general internists with > 1 patient with SLE were searched for cases of SLE diagnosed between 1980 and 1996. A random survey of 20% of family physicians serving this population suggested that > 85% of all SLE cases were identified. Demographics, SLE Disease Activity Index (SLEDAI) scores, Systemic Lupus International Collaborating Clinics/American College of Rheumatology (SLICC/ACR) damage scores, clinical manifestations, and therapy for NAI were contrasted with the results in Caucasians (CAUC). **RESULTS:** We identified 257 cases meeting the ACR criteria for SLE diagnosed between 1980 and 1996. There were 49 NAI cases, resulting in a prevalence of 42.3/100,000, compared to a prevalence of 20.6/100,000 for the remainder of the population. NAI patients were younger at diagnosis, had higher SLEDAI scores at diagnosis, and had more frequent vasculitis, proteinuria and cellular casts. There were no treatment differences at diagnosis or at 2 years, but NAI patients were significantly more likely to receive treatment with prednisone or immunosuppressives at the last clinic visit. The NAI patients had similar damage scores at diagnosis, but significantly higher scores at 2 years and at the last clinic visit. NAI ethnicity increased the likelihood of death more than 4-fold. **CONCLUSION:** The prevalence of SLE was increased 2-fold in the NAI population. NAI patients had higher SLEDAI scores at diagnosis and more frequent vasculitis and renal involvement, required more treatment later in the disease course, accumulated more damage following diagnosis, and had increased fatality.

2. Systemic lupus erythematosus in the pediatric North American Native population of British Columbia .J

Rheumatol. 2006 Jan;33(1):161-3. Houghton KM, Page J, Cabral DA, Petty RE, Tucker LB.

OBJECTIVE: To compare the estimated prevalence and the phenotype of pediatric systemic lupus erythematosus (SLE) in a North American Native population with other ethnic groups. **METHODS:** We performed a retrospective chart review of all patients with SLE currently followed at the single tertiary care pediatric rheumatology clinic in our province. Data collected included demographic characteristics, family history, classification criteria for SLE, laboratory tests at diagnosis, SLE Disease Activity Index (SLEDAI) at presentation, and Systemic Lupus International Collaborating Clinics (SLICC) damage index at 6 months. **RESULTS:** The prevalence of SLE in our pediatric Native population is 8.8 per 100,000 (n = 6) compared to 3.3 per 100,000 in the non-NAI population (n = 34) (p = 0.037, Fisher's exact test; OR 2.6, 95% CI 1.1-6.3). Family history of rheumatic disease is more common in our Native children (5/6, 83%) compared to non-Native children (5/34, 15%) (p = 0.002 Fisher's exact test; OR 29, 95% CI 2.8-303.3). The sample size is too small for reliable interpretation of disease phenotype, autoantibodies, disease activity, and disease damage measures. **CONCLUSION:** There is an increased prevalence of SLE and familial autoimmunity among Native children in our population. Public health measures to screen children at risk may detect early disease and may reduce disease morbidity.

3. Rheumatic diseases in North America's indigenous peoples. *Semin Arthritis Rheum.* 1999 Jun;28(6):368-91. Peschken CA, Esdaile JM.

OBJECTIVES: There are at least 3 million North American Indians and Eskimos in North America. The epidemiology of rheumatic diseases in Native North Americans differs from that described for the remainder of the North American population. An enhanced understanding of rheumatic diseases in these indigenous people may provide valuable clues to the cause of these disorders and improve rheumatologic care. **METHODS:** The world literature was searched for all reports of rheumatic diseases in North American Indians and Eskimos. The reports were reviewed and the findings summarized by disease process. **RESULTS:** Many Native American groups have high prevalence rates of rheumatoid arthritis (RA), systemic lupus erythematosus, connective tissue diseases, and spondyloarthropathies. There appears to be a correlation between the pattern of rheumatic diseases in Native North Americans and the patterns of migration and ancestry. In general, Amerind Indians have increased rates of RA and connective tissue disease, while Na-Dene Indians and Eskimos have high rates of spondyloarthropathies. The RA seen in Native Americans is generally severe, seropositive, with an early age of onset, and frequent extraarticular manifestations. Many Native American groups have very high frequencies of the RA shared epitope. The majority of Native American and Eskimo groups also have high frequencies of HLA-B27, and some of the world's highest prevalence rates of spondyloarthropathies are described in these groups. Although some groups show a marked tendency to develop either Reiter's syndrome or ankylosing spondylitis, psoriatic and enteropathic arthritis are rare. **CONCLUSIONS:** The excess rheumatic disease seen in this population is most likely genetic in origin. Because of the combination of high rates of rheumatic disease and relative genetic homogeneity, Native North Americans represent a singular opportunity to study genetic contributions to rheumatic disease. For clinicians, the index of suspicion for rheumatic diseases in North American Indians and Eskimos should be high, and the severe disease and sometimes atypical presentations kept in mind.

4. Chronic arthritis in children and adolescents in two Indian health service user populations. *BMC Musculoskelet Disord.* 2004 Aug 27;5:30. Mauldin J, Cameron HD, Jeanotte D, Solomon G, Jarvis JN.

BACKGROUND: High prevalence rates for rheumatoid arthritis, spondyloarthropathies, and systemic lupus erythematosus have been described in American Indian and Alaskan Native adults. The impact of these diseases on American Indian children has not been investigated. **METHODS:** We used International Classification of Diseases-9 (ICD-9) codes to search two Indian Health Service (IHS) patient registration databases over the years 1998-2000, searching for individuals 19 years of age or younger with specific ICD-9-specified diagnoses. Crude estimates for disease prevalence were made based on the number of individuals identified with these diagnoses within the database. **RESULTS:** Rheumatoid arthritis (RA) / juvenile rheumatoid arthritis (JRA) was the most frequent diagnosis given. The prevalence rate for JRA in the Oklahoma City Area was estimated as 53 per 100,000 individuals at risk, while in the Billings Area, the estimated prevalence was nearly twice that, at 115 per 100,000. These rates are considerably higher than those reported in the most recent European studies. **CONCLUSION:** Chronic arthritis in childhood represents an important, though unrecognized, chronic health challenge within the American Indian population living in the United States.

5. Disparity in Lupus Rates Calculated as Reported vs. Expected Rates of Lupus for American Indians by Service Area, IHS record review by the National Indian Women's Health Resource Center. Unpublished study.

IHS Area	Total Pop.	Expected @ 15/100,000	Expected @ 50/100,000	Reported	Disparity @ 15/100,000	Disparity @ 50/100,000
Aberdeen	100,441	15	50	219	14.6	4.4
Alaska	107,555	16	53.5	116	7.25	2.2
Albuquerque	81,475	12.2	40.7	95	3.3	2.3
Bemidji	92,597	13.9	46.3	123	8.9	2.7
Billings	57,514	8.6	28.7	107	12.4	3.7
California	131,005	19.6	65.5	91	4.6	1.4
Nashville	76,587	11.5	38	63	5.5	1.65
Navajo	219,310	32.8	109	119	3.6	1.1
Oklahoma	281,310	47	156	591	12.6	3.8
Phoenix	146,777	22	73.5	196	8.9	2.7
Portland	155,876	23.4	78	223	9.5	2.9
Tucson	285,677	4.3	14	81	19	5.8
TALS	1,511,135	226	754.5	2,024	8.9	2.7