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*Our New Directeur of the National (Forty and Eight) Carville Star Committee.*  
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## Stanley Stein

**Founder - Editor, 1941 - 1967**

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The purpose of **The Star** is to: 1) Promote an educated public opinion of Hansen's disease, 2.) Furnish vocational rehabilitation for interested patients.

Views expressed in **The Star** are those of patients of the Gillis W. Long Hansen's Disease Center at Carville, Louisiana, except in the case of direct quotations or signed articles.

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# CATARACT SURGERY WITH POSTERIOR INTRAOCULAR LENS IMPLANTATION IN HANSEN'S DISEASE PATIENTS

Van C Joffrion, MD\*, William R Williamson, MD\*\*, Kirk H Webster, MD\*, and Gail Miller, RN.

Multibacillary Hansen's Disease can result in serious ocular pathology with resultant chronic inflammatory eye disease and loss of visual acuity. Patients with Hansen's Disease are also victims of the usual degenerative processes that affect the eye the most common of which are cataracts. Cataract extraction, which today is commonplace and effective, might be denied Hansen's Disease patients because of the underlying ocular pathology and potential for adverse events. Many fellow ophthalmologists have requested that our results of cataract surgery with intraocular lens implantation be reported.

## Introduction:

Cataract surgery on Hansen's Disease patients requires more variable techniques than routine cataract surgery due to dry eyes, frequent chronic iridocyclitis and occasional corneal opacities. Retrobulbar injection was superior to topical anesthesia because the procedure was often longer and more complicated than routine cataract surgery. Phacoemulsion has proven to be the best technique, although the patient with a cloudy cornea may have to undergo extracapsular cataract extraction.

## Materials and Methods:

From January 1994 through January 2001 all patients undergoing cataract surgery at the National Hansen's Disease Programs, Baton Rouge, Louisiana were selected for chart review. Forty-six patients, 24 females and 22 males, age 33 years to 88 years were the subjects of the review. All patients were selected for cataract surgery on the basis of sufficient decrease in visual acuity to alter activities of daily living. Surgery was delayed several months in patients with iridocyclitis while the intraocular inflammation was brought under control and the eye remained inflammatory free. Informed consent was obtained from all the patients. The surgery was performed by William R Williamson, MD. at the Outpatient Surgery

Center of the Williamson Eye Center in Baton Rouge, Louisiana. Phacoemulsion was performed through a clear cornea temporally and was begun with a 3 mm double-stepped incision followed by a small stab incision 90 degrees from the temporal wound. A viscoelastic material was injected at this point as it is frequently necessary to mechanically dilate the pupil and any posterior synechiae can be manually broken at this stage. A 5 mm continuous tear capsulotomy and hydrodissection with balanced salt solution was performed. If the pupil could not be adequately dilated, a sector iridectomy was preferable to mechanical stretching devices. Later the sector iridectomy can be repaired with a 10-0 Prolene suture. Phacoemulsion was then performed in the "divide and conquer" technique followed by careful irrigation and aspiration. A posterior foldable silicon plate intraocular lens was then placed into the capsular bag. If the anterior capsulotomy has radial tears or was too large, a three-piece foldable silicon lens was used instead of a plate lens. Following the lens implantation the viscoelastic material was removed. The wound generally self-seals without a suture but if there was leakage, a 10-0 nylon suture was placed temporally and the knot rotated into the cornea. The suture was removed 1 week post surgery.

## Results:

Patients were judged to have a good operative result if the postoperative visual acuity was improved to 20/50 in the operated eye. Table 1 shows thirty-five patients with good operative results. Any complications in these patients are noted with the appropriate medical or surgical intervention. Table 2 shows eleven patients with suboptimal results. In each instance the failure to achieve an improved visual acuity was determined not to be the result of the cataract surgery but due to a pre-existing eye problem such as chronic uveitis, exposure keratitis with progression or a degenerative process such as macular degeneration or diabetic retinopathy. It should be noted

\*National Hansen's Disease Programs, Baton Rouge, Louisiana. \*\*Williamson Eye Center Baton Rouge, Louisiana

that of the thirteen eyes operated on in this group, post-operatively the vision had improved in nine eyes, remained the same in one eye and became worse in three eyes. The final achieved visual acuity in patient #44 is unknown because he was lost to medical follow-up. In the thirty-five patients with good overall results, it was noted that many of the patients developed opaque posterior capsule and it was our observation that this process seemed to develop more rapidly following surgery than the general population. The eyes responded well to YAG laser capsulotomy. It was our experience that patients with a history of iridocyclitis had three problems with increased frequency compared to those without.

- 1) opacification of the posterior capsule
- 2) post-operative inflammation required more intensive steroid therapy for a longer period of time but in all instance the pre-operative visual acuity was achieved.

- 3) Pupillary entrapment of the intraocular lens due to scarring and shrinkage of the inflammation.

Discussion:

Cataract surgery with posterior chamber intraocular lens implantation is a safe and beneficial procedure for the vast majority of Hansen's Disease patients. The surgery is often more complicated than in the general population and a well trained and experienced surgeon is necessary to achieve good results. Iridocyclitis needs to be well controlled for several months prior to cataract surgery, the surgery is more complicated, and post-operatively more intensive and prolonged steroid therapy is required. It has been found that silicon seems to be slightly less reactive than PMMA lenses in Hansen's Disease patients. The authors encourage all Hansen's Disease Programs to provide cataract surgery with posterior chambers intraocular lens implantation to the patients with confidence that good results are the rule and that patients benefit greatly from the procedure.

Table 2. Suboptimal Results Following Cataract Surgery

Patient	Age	Sex	Pre-op Acuity	Post-op Acuity	Remarks
1	73	F	20/200 OS	20/100 OS	Severe Interstitial keratitis OU
5	68	M	10/200 OD 20/70 OS	20/70 OD 20/70 OS	Langophthalmos, Severe Exposure Keratitis
7	65	M	7/200 OD	20/200 OD	Degenerative Cornea Transplant 1996
15	79	F	3/200 OD	5/200 OD	Macular Scar Macular Degeneration
17	52	F	5/200	20/100 OS	Drusen, Macular Degeneration
24	63	M	4/200 OS	20/200 OS	Chronic Iridocyclitis OU Post Synechiae OS
30	88	F	<20/200 OS	20/60 OS	Macular Degeneration
34	80	F	Hand Motion OS	20/70 OS	Langophthalmos, Severe Exposure Keratitis
35	67	M	20/100 OD	20/70 OD	Central Corneal Scar
37	61	M	20/70 OD 2/200 OS	20/200 OD 20/70 OS	Diabetic Retinopathy Macular Degeneration OD
44	33	M	20/70 OD	20/400 OD	Patient lost to follow-up Uveitis, Vitritis Slow Resolution with Topical Steroids

Table 1

ID	Surgical Date		Age	Sex	Uveitis	Pre-op VA		Post-op VA		Complications	Corrective Actions	DX	Remarks
	Right Eye	Left Eye				Right Eye	Left Eye	Right Eye	Left Eye				
2	5/5/92	2/18/92	73	F	+	20/50	20/200	20/30	20/30			LL	
3	3/19/96	12/2/96	79,69	M	+	20/100	20/200	20/30	20/30			LL	OS Extracapsular
4	6/2/99	6/9/99	75	F	-	20/50	20/50	20/25	20/20			LL	
6	11/19/91	8/31/93	74, 76	M	+	20/200	20/50	20/25	20/25	OPC OD	YAG 4-3-95 OD YAG 1-31-97 OS	LL	Exposure Keratitis OU
8	6/28/94	7/19/94	60	F	-	20/70	20/50	20/40	20/30	OPC	YAG 11-28-97 OD YAG 11-21-97 OS	LL	
9	3/4/97	2/26/97	77	M	-	20/60	20/60	20/40	20/40	OPC	YAG Not Done	DIMORPH	Dementia
10	4/10/74	9/14/81	56, 63	F	+	20/60	20/200	20/20	20/20-1	OPC		LL	2 <sup>nd</sup> Implant OD 4-93 20/25
11	10/14/97	10/21/97	63	F	-	20/70	20/50	20/20	20/20	OPC	YAG 11-18-96 OD	LL	Lagophthalmus Severe Exposure Keratitis
12	7/14/95	7/21/95	84	F	-	20/200	20/70	20/50	20/50	OPC OU	YAG 4-13-98 OU	LL	Glaucoma
13	10/6/92	11/15/94	66,68	M	-	20/200	20/400	20/30	20/25		Parenteral & Topical Steroids	LL	Glaucoma, H Zoster OS
14	7/13/99		76	F	-	20/40		20/30				LL	
16	9/10/96	9/24/96	76	M	-	20/80	20/80	20/40	20/50	CME OS		LL	5-30-00 VA 20/25 OU
18	12/12/99	9/28/99	78	F	-	20/100	20/40	20/40	20/50	OPC	YAG 12-20-99 OS	DIMORPH	VA 20/40 OU P.H. 20/25 12-01
19	10/30/01	8/2/94	66, 73	M	-	20/200	20/200	20/25	20/30			LL	
20		10/27/98	76	F	-		20/50	20/30	20/30	OPC OS	YAG 6-5-01	LL	Diabetes
21	8/17/93	8/4/93	76	F	+	20/200	20/100	20/30	20/30			LL	
22	4/8/87		61	F	-	20/100	20/30	20/30	20/30			LL	*Extracapsular Cataract Extraction
23	10/16/91	11/30/90	47, 48	M	+	20/60	20/200	20/40	20/50	Choroidal Edema OS Uveitis OD	Topical Steroids Topical Steroids	LL	
25		11/20/90	77	M	-		20/50					LL	
26	6/7/94	5/17/94	65	M	-	20/200	20/50	20/50	20/30	OPC	YAG 2-16-93 OS	LL	
27	11/15/94	9/3/91	73, 76	M	-	20/200	4/200	20/30	20/40	OPC	YAG 2-3-97 OS	LL	Amblyopia OD
28	2/18/92	3/26/97	66, 71	M	-	20/70	20/70	20/40	20/25			LL	
29	5/2/94	5/10/94	45	F	-	20/70	20/40	20/30	20/25			BL	
31	1/30/97	6/1/93	69, 73	F	-	20/200	20/30	20/40	20/40	OPC OS	YAG 12-14-93 OS	LL	* Also CME OD Resolved
32	7/26/94	7/19/94	70	M	-	20/70	20/70	20/25	20/40	Corneal Degeneration Mild OPC OS	Topical Steroids	LL	
33	2/10/98	3/3/98	63	M	-	20/200	Hand Motion	20/30	20/30			LL	
36	5/17/94	6/7/94	81	F	-	1/200	20/200	20/60	20/60	OPC OD	YAG 10-20-98	LL	
38	1/23/95	1/30/95	63	F	-	4/200	2/200	20/30	20/40	OPC OS		LL	
39	8/31/93	9/22/93	66	M	-	20/80	20/100	20/30	20/50			DIMORPH	Lagophthalmus, Exposure Keratopathy
40	11/12/93	10/26/93	55	F	+	20/200	20/200	20/25	20/25	OPC	YAG 7-5-94 OD	LL	
41	5/4/94		81	F	-	20/200	20/30	20/30	20/30	OPC	YAG 7-5-94 OD	LL	
42	7/25/94	7/18/94	65	F	+	7/200	5/200	20/50	20/50	OPC OD	YAG 12-21-98 OD	LL	Macular Degeneration OD
43	3/24/92	1/13/98	74, 79	M	-	2/200	20/200	20/40	20/40			LL	
45	7/18/94	7/25/94	80	F	-	20/80	20/200	20/40	20/30	OPC OU		LL	Lost to Follow-up
46	2/3/98	2/10/98	40	F	+	2/200	12/200	20/100	20/40			LL	

OPC= Opaque Posterior Capsule CME= Cystoid Macular P.H.= Pin H OS= Left Eye  
 YAG= YAG Laser Capsulotomy ION= Ischemic Optic Ne OD= Right I OU= Both Eyes

# THE COLORFUL CHARACTERS OF CARVILLE

by Julia Rivera Elwood

Part 5

## HISTORICAL FIGURES

### HANSEN

Gerhard Henrik Armauer Hansen, of Bergen, Norway, discovered and identified *Mycobacterium leprae* in 1873. This event was not only important to those in leprosy work, but to all mankind since, according to Dr TM Vogelsang, "it was the first time in history that a bacillus was demonstrated as the causative agent of a chronic disease."

Dr Hansen, sometimes called a "lifetime student of leprosy," devoted his life to several of its aspects which included epidemiology, etiology, prevention and institutional management. Hansen was a brilliant and industrious student. When he joined the staff of the hospital for leprosy, he met Dr Danielssen, the physician in charge, who later became his friend, science associate and father-in-law.

Leprosy was found in Norway in the middle of the 19th century and Hansen was already experimenting with it. He tried to transmit it to animals and to himself without success. He was ahead of his time in thinking that leprosy was not only specific and infectious, but caused by a bacterium.

The fight to eradicate leprosy from Norway was led by Hansen. He promoted the idea of isolation of patients in hospitals because it was the major way to keep the disease from spreading. He fought for stricter laws concerning patients with leprosy and the cases started declining in number. Although the decline happened partly because of improved living and economic conditions in Norway, some of the credit must go to Hansen for his efforts to control leprosy in that country.

### ADJUTANT GENERAL ALLEN JUMEL

Adjutant General Allen Jumel's connection to the Carville Center was through his being appointed to the Board of Control for the Louisiana Leper Home. When the patients arrived, he was there to meet them as a member of the board and also as the sheriff of Iberville Parish.

He was born at West Point, NY in 1835 and shortly after that, his family moved to Louisiana. Jumel attended Centenary College and later entered the Confederate service as captain. He was engaged in steamboating until 1876 when he elected auditor of the state. After serving in the Louisiana Legislature as Senator and Representative, Jumel was appointed Adjutant General of Louisiana.

It was during his tenure as a legislature that he played a part in establishing the hospital at Carville. In 1894, the legislature voted to buy a site designed solely for the care of leprosy patients. According to JA Jumel, Allen Jumel's grandson, his grandfather's life was threatened as a result of his efforts to help establish the hospital. The Daily Picayune reported in an article in 1894 about the arrival of the first patients at Carville that Capt Allen Jumel, then sheriff of Iberville Parish and a member of the Board of Control, welcomed the patients and after a comment was made that the surrounding community might object to the patients being at the home, stated that he would "stand by the almost friendless patients if it cost him his life."

It goes on to say: Jumel rode up on his horse to welcome the patients and Dr Isadore Dyer. Captain Jumel made an impressive picture as he sat on his pretty mare. He has gray hair and a silver-gray beard, and looked a typical Louisiana lord of the land.

### DR ISADORE DYER

Dr Isadore Dyer, a dermatology professor and dean of the medical department at Tulane University, New Orleans, was selected to be president of the Board of Control of the Louisiana Leper Home in 1894.

Chiefly through Dr Dyer's efforts, a bill was introduced in the Louisiana legislature providing for an annual appropriation of \$10,000 for the funding and maintenance of a hospital for leprosy. Overcoming several hurdles having to do with fear and rejection from the citizens of two New Orleans suburbs, Dr Dyer went forward with his plan of finding a distant place for the patients who were housed at different sites in New Orleans. He was successful in leasing the Indian Camp, and old sugar plantation which had been abandoned and was in ruins in Iberville Parish. Dr Dyer accompanied the first seven patients, two women and five men, to Carville, their new home, on November 30, 1894. Because Dr Dyer was the recognized authority on leprosy at the time and the first physician to introduce chaulmoogra oil in a US hospital, he was the star witness before the Senate for the establishment of a national leprosarium in the United States. His 21-page testimony was a strong plea for federal interest in the problem and carried weight with the committee. The hospital converted to federal auspices in 1921.

The Daily Picayune stated, "Only in our own era has the word 'leper' begun to lose its ancient connotation. The emphasis is now on the unfortunate human being victimized by one of the most insidious of maladies, not on the pariah or outcast. This enlightened change of attitude on the part of the public was not an accident. It was fostered by the unselfish and unremitting labors of noble-hearted men and women who wished not so much to save the world from contamination of the leper as the leper from the callousness of the world. Of such a stamp ... was Dr Isadore Dyer. . ."

It has been said (and it is fitting) that this good-hearted physician in every sense epitomizes the high purpose to which the leprosarium at Carville is dedicated and that Carville is his monument

### **DR GUY H FAGET**

The sulfones, the first fully successful treatment for Hansen's Disease, were introduced at Carville by Dr Guy H Faget, medical officer in charge of the then US Marine Hospital #66, in 1941. They changed the treatment and management of HD forever. Sulfones are still used as treatment for HD in conjunction with other drugs in today's multi-drug therapy.

The first sulfone tried at Carville was Promin by injection. Later, since the patients could not tolerate so many intravenous injections, it was distributed in tablet form by the name of Diasone (a sugar coated tablet) and Dapsone, a small white pill.

After graduating from Tulane University, New Orleans, in 1914, Dr Faget made the United States Public Health Service his life's career. He interned at the US Marine Hospital in New Orleans, and served at Marine Hospitals in San Francisco, Seattle, Ft Stanton, NM, and New Orleans before coming to Carville.

Born in New Orleans in 1891, Dr Faget was married and had three children. He spoke French fluently and some Spanish. For a few years, he served in British Honduras under the Colonial Service of the British government where he treated tropical diseases, leprosy included.

Throughout his professional life, he was a prolific writer authoring many publications with subjects ranging from tuberculosis, malaria, pneumonia, and Hansen's disease.

### **THE DAUGHTERS OF CHARITY OF ST VINCENT DE PAUL**

The Sisters of Charity, as they are commonly known, came to Carville to take care of the leprosy patients in 1896. When the Home first started, Dr LA Wailes was a physician who was alone taking care of the patients at Carville. After one year, there were 27 patients at the hospital and Dr Isadore Dyer, president of the Board of Control, decided to request the services of the Daughters of Charity to nurse the patients and manage the home. Before the Sisters decided, they sent Sr Agnes Slavin from Charity Hospital, New Orleans, to assess the situation.

She wrote a very discouraging report about the deplorable conditions of the buildings to the superior recommending that the Sisters not be sent to Carville until some arrangements could be made for proper housing for them. Father Lennon, Director of the Sisters of Charity in Emmitsburg, MD, came to visit the Home as a result of the letter and decided that this was a mission which the Sisters should take on.

Negotiations began and a contract was signed on March 25, 1896. It stated that the Sisters would receive a salary for their services. Also stated in the agreement was that they would be responsible for the domestic management, the supervision of the household, culinary, laundry and nursing for the home.

In a report to the Board of Control in 1898, MD Lagan wrote: "It is with greatest pleasure we refer to the fact that our duties are lightened and our anxieties diminished by the knowledge that our plans and regulations are always faithfully executed by the Sister Superior in charge, and three others of that noble order, the Sisters of Charity. . . . We cannot say enough in praise of our four devoted and heroic Sisters of Charity, who are giving their lives to this cause without other recompense than a modest allowance for clothing and incidentals. The world outside knows but little of the difficulties of their undertaking. Without ostentation, they have the courage to conquer the dreariness of the situation and find contentment in catering to the wants, alleviating the sufferings and devising ways of making the lepers committed to their care as happy as it is given such unfortunates to be."

The Sisters were the first social workers. They encouraged the patients to find ways to pass the time so they would not dwell on their condition. Some of them planted flowers, vegetables and fruits; others tobacco. Their aim was to keep them busy.

Another concern of the Sisters was the way they buried the dead patients. One of them, Sister Beatrice, wrote, "Before we took charge of them they were thrown like dogs into the grave the same day they died. I have insisted on a Christian burial as we understand it."

Through the years, a total of 112 Sisters have served in the capacity of nurses, dietitians, pharmacists, x-ray technicians, photographers, and historians. In 1957, the highest award given by the Department of Health, Education and Welfare was presented to the Sisters for outstanding contribution to the work of the Department.

### SISTER BEATRICE HART

*Reprinted in part from a booklet found in the Sisters' Archives about Sister Beatrice Hart's life (no author, no date).*

As soon as it was known throughout the Community that this new field was open to their devotedness, scores of Sisters eagerly solicited the favor of being chosen for the work. From the number presenting themselves, four were selected. Sister Beatrice Hart being recalled from the hospital at Lowell, MA, of which she had been in charge for 22 years, to head the little band. Born of a splendid Catholic family, in Boston, in 1841, Sr Beatrice entered the Community at the age of 23. The Sisters who went so quietly and so efficiently about her daily round of duties, ambitioned to do still greater things for the Master. Sr Beatrice herself felt that this "second vocation" was sent by God, and when asked what were her sentiments when she received word that she had been selected for the Leper Home, said, "When I offered myself to serve the lepers, I was sure that my Superiors would understand that I responded to the call of God and that they would accept me, I am not surprised and I experience a joy and a happiness beyond the power of words to express."

With her three companions, Sisters Mary Thomas Stokum, Annie Costello, and Cyril Coupe, Sr Beatrice sailed from New Orleans, April 26, 1896, on a river packet. A large delegation had gathered to see them depart for a destination mentioned only in whispers -- "The Leper Land." As soon as it becomes known that the Sisters of Charity are there, the lepers, now roaming at large, will take courage and come into our retreat. The very name of Sisters of Charity inspires confidence and that is what we need in our work. The Board alone could not command that -- the Sisters of Charity can."

In her first letter, Sister Beatrice tells of the welcome they received. "As we could see that all those who were able to be out were on the porches, we went first to these, and told them that we had come to stay, wishing to do all that we could to comfort their lonely, suffering condition. It was

touching to see the happiness of these poor people when they caught sight of the Sisters. They almost wept for joy. "Yes, yes," I answered to their inquiries, "we have come to stay with you always, you need not be afraid, we shall not go back."

Our first day we spent in preparation for Mass on the following day. A large basement room was selected, our first care being to remove dust and spider webs. The Sisters of New Orleans had vied with one another to furnish ornaments for the altar. In the evening we felt quite proud of our work, but greater far was our joy the next morning to see our little congregation fill the Chapel. Sixteen of them approached the Holy Table. The Chaplain addressed them in simple, touching words, telling them we had come to labor among them, to bring back some of the early happiness of home and mother into their sad, deprived lives, to make them happier and better, and when he bade them lift up your hearts, sobs could be heard throughout the Chapel and we could not refrain from mingling our tears with theirs.

Anything less than Sr Beatrice's all-embracing charity would scarcely have sufficed to make of "Indian Camp" a home for either Sisters or patients. Both suffered the extremes of discomfort. For the patients' use, a few old slave cabins, deserted since slavery days, had been patched up. These were located a considerable distance apart, on low, marshy ground covered during eight months of the year with a dank, rank growth of weeds. A part of each Sister's equipment was a little hand lantern kept ever ready by her bed to guide her to such sufferers as needed her attention at night. The only heat in the cabins was furnished by small fireplaces around which the patients sometimes burned their insensitive extremities in the efforts to keep warm; over these same fireplaces must be heated the water to bathe ulcerated feet and hands and faces. Cisterns furnished the only water supply and, in times of drought, water was brought from the Mississippi in a barrel and used with no other purification than such as was furnished by a few hours settling.

Much can be gleaned of the work from Sr Beatrice's letters. In May, 1896, she writes: "How vividly they recall to my mind the words of St Vincent when he said: 'Amongst the poor you will sometimes find those who have scarcely the semblance of a human being.' However, afflicted as they are, they are quite cheerful and enter into the simple amusements we try to provide for them." The victims are scarce able to do more than help themselves a little, and as it is impossible to secure hired help, the work devolves upon the Sisters. Often we are glad by the best management, to find time for our spiritual exercises.

Hardships and sufferings that could not weaken her indomitable spirit could yet take bodily toll. Towards the fall of 1901, her companions noticed with much apprehension, that



Sr Beatrice showed signs of suffering and fatigue. Frequent attacks of malarial fever, dread visitant of the swamps, left her completely debilitated.

During the few days that intervened before her death, Sr Beatrice suffered intensely. Beyond their love and devotion, her companions could offer little in the way of alleviation. They were obliged to move her bed from one side of the room to the other as the rain, driven by the wind came in first from one direction and then from another. A doctor summoned from New Orleans confirmed their fears that death was fast approaching. On the morning of September 6, 1901, death terminated her voluntary exile. That she died among the lepers, a victim of overwork and malarial fever, rather than of leprosy, detracts nothing from her sacrifice.

It is good to know that the seed of this heroic life has brought forth much fruit. Public and private charity soon made more liberal provision for the patients, and gradually the Sisters saw real transformations. For the nursing and dietetic service of this number of patients there are 14 Sisters of Charity; Sisters who go about their duties with the same joyousness that marked their predecessors; Sisters who say simply, as said Sr Beatrice: "We think the patients are happier because we are here."

#### **SISTER BENEDICTA ROACHE**

Sister Benedicta Roache, Sister Beatrice's successor, was a staunch supporter of the patients. She would stop at nothing to bring comfort to them. The following story is representative of how energetic and forceful she was. After the water supply failed, sisters and patients had to haul water a hundred or more yards with no purification of it except settling. They were exasperated by the fact that they hauled the water in barrels on wheelbarrows and by the time they climbed up and down the levee, there was little water left inside. Because several letters of complaints went unanswered, Sister Benedicta went to New Orleans to speak to the Board of Control. The men told her that nothing could be done and the government disapproved of borrowing money. Realizing that she was getting nowhere, Sister Benedicta proceeded to tell the Board that she would be at St Vincent's Infant Asylum until 4:00 pm -- if she did not hear from them by that time, she would make a public appeal through the newspapers. The funds were immediately borrowed! Such encounters were not common, Sister Benedicta usually was given her way.

When Sister Benedicta, who worked at Carville for 18 years, arrived here, the patients lived in run-down slave cabins to which the Sisters would wade through the mud to get to them when patients needed them at night. After they hauled

the water in barrels from the river, they would have to heat it up over a fireplace to give patients their hot foot baths. It was an uncivilized wilderness.

Her humor would surface once in a while and when she spoke of insects which bothered the Sisters and patients, she said, "The bug of every nationality is after this Roache." (Her last name was Roache!)

About the forth of July Celebration, Sister Benedicta wrote in one of her letters: "The chief feature of the Forth of July treat was half barrel of beer for which the men had made request two months before. It had been so long since they had any that they forgot how it tasted. It is better to give them a treat once in a while openly as otherwise they manage to get it on the sly. An open treat keeps a good spirit among them. Pretzel, Lager beer, music and fireworks made up their day."

Sister Benedicta had a soft spot for children and when boys of ages six to seven years old came to Carville, she begged for "separate quarters for them to insure good morale, as well as physical care, and to prevent them from seeing the horrible ravages of leprosy in some of the cases."

She demanded proper care and treatment for the patients writing numerous letters to the Legislature on their behalf. Sister requested a refrigeration plant, more money for improvement, separate quarters for young patients, and at times wrote directly to the Governor himself!

Loved by all, Sister Benedicta died at Hotel Dieu in New Orleans in 1931.

Continued in next issue



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## **Notice**

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addressed to:**

**David R. Rabius  
CORREONDANT NATIONAL  
777 N. Meridian Street  
Indianapolis, IN 46204-1170**

**(317) 634-1804 Fax: (317) 632-9365  
e-mail: [voiturenational@msn.com](mailto:voiturenational@msn.com)**



# Women Affected By Leprosy Seek Freedom From Stigma

By José Ramirez, Jr.

On June 14, 2002, an extraordinary event occurred in Auburn, New York, at the home of Harriet Tubman. Ms Tubman was a leader of the Underground Railroad, risking her life to guide 300 slaves to freedom and in the process, making the spirits of her ancestors from Ghana proud.

On June 14th, Ms Tubman's own spirits were resurrected. This happened when her great grand niece, who serves as a guide to the museum-like home of the great liberator, met two women from Ghana. Ironically, these two ladies, embraced in traditional dress, came to the United States to talk about their slavery to stigma. The women were visiting Seneca Falls, minutes away from Auburn, to participate in the "First International Conference on Women Affected by Leprosy."

Harriet Tubman used to tell the persons entombed in slavery to "keep going" whenever they felt hungry, tired and scared; otherwise they would never experience the joys of freedom. The women from Ghana, along with others who arrived from India, Nepal, Korea, Brazil, Japan, Suriname, China, Nigeria and the U.S., have also experienced the humiliation and loss of identity that their ancestors felt as slaves.

Leprosy, also known as Hansen's Disease, is considered to be only "mildly communicable," although the exact mode of transmittal remains a mystery. Something that however does not remain a mystery is the fear that most people have of this grossly misunderstood disease. The end result of this powerful ignorance is that women diagnosed with leprosy have been sterilized against their wishes, their husbands granted a divorce without cause, forced to change their names, ostracized by their families, isolated from society and forced to abort when found to be pregnant. All of these painful experiences have occurred globally, including the United States. In 2002, the U.S. has approximately 6000 persons affected by leprosy, 500 of these in Texas.

Unfortunately, many other women were unable to attend the conference. This occurred, in part, to the more stringent requirements for issuance of visas since

September 11th. Nevertheless, those who attended gathered at the Wesleyan Chapel, site of the first Women's Rights Convention in 1848 where Elizabeth Stanton and 300 others including Fredrick Douglass conceived women's rights. Later, Susan B. Anthony joined forces with Stanton and Douglass to advocate for women's rights.

Magdalena Ramirez, Social Worker at the Houston VA Hospital and 2002 Texas Social Worker of the Year, presented the Keynote address at the conference titled "The Spirit of Women." Ramirez focused her presentation on the kaleidoscope of emotions she experienced when diagnosed with breast cancer. She equated her emotions with the challenges she faced when someone close to her was diagnosed with leprosy who has served as her "role model."

Many of the conference attendees spoke about their gut-wrenching experiences at the First Presbyterian Church where another social worker, Alice Paul, proposed the First Equal Rights Amendment. The ladies celebrated their newfound courage to speak against the injustices they were forced to endure by embracing seven women from the U.S. honored at the National Women's Hall of Fame, where the first inductee was another social worker, Jane Adams. Finally, the women slept in homes around Seneca Falls that Harriet Tubman used in her network to freedom.

Leprosy is a disease that can cause severe disabilities if left untreated. Regrettably, the disease can go untreated for decades because only a small fraction of physicians ever suspect leprosy as the culprit to this psychologically crippling disease. Once properly diagnosed, leprosy can be cured within a matter of months. However, the road to emotional recovery can take decades. The conference did open up the opportunity for the ladies affected by leprosy to pave the road to freedom.

Women at this first of its kind conference made history by finally voicing their pain, and by passing a resolution declaring their empowerment. Some of their declarations included:

- Different organizations with a focus on leprosy should differentiate between the needs of those diagnosed in the 21st century and those prior to the year 2000.
- The World Health Organization should recognize the harm resulting from past practices which condoned the separation of women diagnosed with leprosy from their children, and sponsor:
  - workshops to address healing and conciliation between mothers and their children.
  - workshops to address healing for parents bereaved by their right to have children.
- All religious faiths should work collaboratively to change gross misconceptions that leprosy is synonymous with “sin.”
- Medical schools should initiate curricula which address psychosocial aspects of being diagnosed with leprosy or other misunderstood diseases.
- Governments should make funding available for women affected by leprosy to record their experiences in oral histories so that this documentary of injustices is not repeated by other generations.

Seneca Falls, N.Y., the town used as the model by Frank Capra for Bedford Falls in the movie *“It’s a Wonderful Life”* again has been touched by many angels - ladies affected by leprosy. These courageous angels, many from Texas, are ready to fight with words and education to cease the painful volleys of stigma.



### A Personal Account ..... (contd from page 10)

*Nicole Holmes was just one of countless participants at the “I Will Go With You” Conference, on June 11-16, 2002 in Seneca Falls, New York. The experience so moved her she was prompted to write this account. Ms Holmes, age 23, is currently working with IDEA to develop an e-mail support group among individuals being treated as outpatients in the United States. Originally from Trinidad, Nicole was diagnosed with leprosy in 1996 at the age of 17 and began treatment in 1997. Despite the additional stresses brought on by the diagnosis, she graduated from college Magna Cum Laude and has married. She comments: “The key to getting well is in our hands. You may not be able to control what is going on inside your body, but the more knowledge you have about leprosy, the more empowered you begin to feel. If for some reason your doctor does not have an answer, then get it yourself. I have found that sometimes the best prevention is self-education.”*

This article was published in the ILEP “Connect” Newsletter No. 7, August 2002.

This was submitted to The STAR for publication by Irma E. Guerra, BSN, MPH  
 Director, ACP  
 with permission from the author, Nicole Holmes, and from Anwei Skinsnes-Law.




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**Corrections:** Vol. 60, No. 4 - p 2

A CONTEMPORARY VISIT TO THE LAND OF MYTH  
 by José Ramirez, Jr.

José and his wife Magdalena went on a two-week tour of Turkey and Greece to gather information on HD. Their visit brought honors and surprises and new information on how leprosy has been and continues to be perceived.



# IDEA First International Conference on Issues facing Women affected by leprosy:

## A personal account

by Nicole Holmes

The conference was a unique experience for me. I have never before been in the presence of such talented and intelligent women, who at the same time managed to be so humble and kind. I felt that I was part of a larger family encompassing the globe, because everyone embraced me with open arms. It was especially fitting to have IDEA's First International Women's Conference in the same town as the First Women's Rights Convention of 1848. A visit to the convention site made me feel nostalgic because I know, that as women with leprosy, we are still struggling for certain rights denied us - just like Elizabeth Cady Stanton and her supporters. Overall, the conference was a wonderful, but three events especially had an impact on me. First, I enjoyed learning about the lives of all the women through the speeches they gave. It was very emotional at times, because of the heartbreak and struggle that these women have been through. Although their cultures are distinct and their stories took place in different parts of the world, the isolation, discrimination, and pain they have endured are similar. Many of the women were forced to make unjust sacrifices largely due to society's ignorance. It was reassuring to hear that many took it upon themselves to change society's view despite the consequences, since they felt obligated to make a difference for generations to come. Secondly, the opening ceremony of the conference was remarkable. The participants from the various countries each wore their national costume and we formed a procession leading into the ceremony. The person representing each country was announced before being seated. The featured speakers spoke so eloquently and some chose to share with us the women who had touched their lives in some way. A candle was lit in remembrance of the First Women's Rights Convention in the colors of women's suffrage - purple, gold and white; as were the flowers that we placed at the wall of the Declaration of Sentiments. At the wall, being

together as a group inspired us to sing and to keep singing, which was a lot of fun. At the ceremony to officially open the IDEA Center for the Voices of Humanity, I enjoyed reading the different banners with stories and pictures of the lives of various people with leprosy. I truly felt that we had a voice and that the Center was a safe haven where our voices could be heard. Viewing the huge quilt consisting of fabric sent by IDEA members from around the world further gave me the assurance that I am part of a larger collection of people. One of the highlights of the ceremony was having certain participants light candles in honor of those who had passed away and had touched our lives in some way. At the end of the ceremony I read my poem Journey, which was fitting since I believe that as women with Hansen's Disease we have all gone down the same path, but that path has had different outcomes. I was touched that that we had the support of the small community of Seneca Falls. They came out to participate in the conference's various events. I know I felt welcomed by them and I'm sure everyone else did as well. Some of the churches in the area hosted our meetings and provided most of our lunches and dinners. The parishioners themselves made the meals and served them. The variety in dishes was delicious.

In conclusion, the conference was a huge success. It brought together a group of women that would not ordinarily have been able to do so. We were able to share our lives, our struggles and our hopes for the future, with IDEA at the forefront. I was really impressed by all the work that the various IDEA chapters around the globe had done. It made me proud to be an IDEA member and gave me the impetus to want to do more.

(contd on page 9)

**Table 7**

**Comparison of mean values of catalase**

Source	D.F	Sum of squares	Mean Squares	F-value	p-value
Between Groups	6	6227406.6	1037901.1	75.84	<0.00001
Within Groups	144	1970644.0	13685.0		
Total	150	8198050.6			

**Duncan' Multiple Range Test:**

Mean	Group	III	V	II	IV	VII	I	VI
639.8	III	-	-	-	-	-	-	-
721.5	V	**	-	-	-	-	-	-
850.9	II	**	**	-	-	-	-	-
894.6	IV	**	**	-	-	-	-	-
1142.0	VII	**	**	**	**	-	-	-
1156.3	I	**	**	**	**		-	-
1166.4	VI	**	**	**	**	-	-	-

**Table 8**

**Comparison of mean values of GST**

Source	D.F	Sum of squares	Mean Squares	F-value	p-value
Between Groups	6	17.0939	2.8490	75.049	<0.00001
Within Groups	144	5.4664	0.038		
Total	150	22.5603			

**Duncan' Multiple Range Test:**

Mean	Group	III	V	II	IV	I	VI	VII
1.7184	III	-	-	-	-	-	-	-
1.8775	V	**	-	-	-	-	-	-
1.9868	II	**	-	-	-	-	-	-
2.1960	IV	**	**	**	-	-	-	-
2.4196	I	**	**	**	**	-	-	-
2.6056	VI	**	**	**	**	**	-	-
2.6630	VII	**	**	**	**	**	-	-

**Table 9**

**Comparison of mean values of glutathione**

Source	D.F	Sum of Squares	Mean Squares	F-value	p-value
Between Groups	6	126.1401	21.0233	558.9258	<0.00001
Within Groups	144	5.4164	0.0376		
Total	150	131.5565			

**Duncan' Multiple Range Test:**

Mean	Group	III	IV	II	V	VII	VI	I
4.24	III	-	-	-	-	-	-	-
4.54	IV	**	-	-	-	-	-	-
4.95	II	**	**	-	-	-	-	-
4.97	V	**	**	-	-	-	-	-
6.17	VII	**	**	**	**	-	-	-
6.31	VI	**	**	**	**	**	-	-
6.72	I	**	**	**	**	**	**	-

**Table 10**

**Comparison of mean values of vitamin E**

Source	D.F	Sums of squares	Mean Squares	F-value	P-value
Between Groups	6	484.52	80.75	29.75	<0.00001
Within Groups	144	390.84	2.71		
Total	150	875.36			

**Duncan' Multiple Range Test:**

Mean	Group	III	V	IV	II	VI	VII	I
13.93	III	-	-	-	-	-	-	-
14.41	V	-	-	-	-	-	-	-
14.97	IV	**	-	-	-	-	-	-
15.43	II	**	-	-	-	-	-	-
16.95	VI	**	**	**	**	-	-	-
17.63	VII	**	**	**	**	-	-	-
19.03	I	**	**	**	**	**	-	-

**Table 11**

**Comparison of mean values of GPX activity in the seven groups**

Source	D.F	Sums of squares	Mean Squares	F-value	P-value
Between Groups	6	12.9591	2.1598	118.6610	<0.00001
Within Groups	144	2.6211	0.0182		
Total	150	15.5801			

**Duncan' Multiple Range Test:**

Mean	Group	III	V	II	IV	VII	I	VI
0.6176	III	-	-	-	-	-	-	-
0.8275	V	**	-	-	-	-	-	-
0.8508	II	**	-	-	-	-	-	-
0.9505	IV	**	**	**	-	-	-	-
1.1825	VII	**	**	**	**	-	-	-
1.3420	I	**	**	**	**	**	-	-
1.5388	VI	**	**	**	**	**	**	-

**Statistical Inference**

There is high statistical significance in the mean values of LPO among the seven group(F=122.9841,P<0.00001), indicating that the mean LPO values are statistically significant across the subjects of the seven groups. Group I (healthy volunteers) had significantly lower LPO than the groups patients. By Duncan's multiple range test for multiple comparison we have observed that the mean LPO value of the patients from Group III and Group II are significantly higher than that of patients from other groups.

There is high statistical significance in the mean value of SOD among the seven groups (F = 127.739, P<0.00001) indicating that the mean SOD value to be statistically significant across the subjects of the seven groups and among the seven groups. Group III patients had statistically significant lower mean SOD than the other group patients, and Group II patients had statistically significant higher mean SOD than the other group patients, from the multiple comparison of patient groups. We can infer that Group I, Group VII, and Group VI are significantly different from the other groups.

There is high statistical difference in the mean values of GPX among the seven groups (F = 242.602, P<0.00001); that means GPX values of the seven groups are statistically significantly different among these groups. Group III patients had lower mean

GPX value and Group I subjects had higher mean GPX values. By multiple comparison test it is evident that Group I and Group VII are statistically significantly different from the other groups.

There is high statistically significant difference in the mean values of catalase among the seven groups ( $F = 75.84$ ,  $P < 0.00001$ ) indicating that the mean catalase values of seven groups are statistically significantly different among these groups. Group III and Group VI patients had lower and higher mean catalase values respectively, and Group VI and Group I and Group II are having statistically higher mean catalase values in comparison with the mean values of other groups.

There is high statistically significant difference in the mean values of GST of the seven groups ( $F = 75.049$ ,  $P < 0.00001$ ); the Group III patients had lower mean GST value and group VII had higher mean GST value. By multiple comparison of these groups, we are able to infer that the mean values of GST of Group VII and Group VI are significantly different from those of the other groups.

There is high statistically significant difference in the mean values of glutathione in the seven groups ( $F = 558.9258$ ,  $P < 0.00001$ ). Group III patients had lower mean glutathione values, significantly different from those of the patients of the other remaining four groups.

There is statistically significant difference in the mean value of vitamin E among the seven groups ( $F = 29.75$ ,  $P < 0.00001$ ). Group III and Group I had significantly lower and higher mean values respectively than the other five groups. The mean values of vitamin E of Group I, Group VII and Group VI are significantly higher than the mean values of vitamin E of the other four groups.

There is high statistically significant difference in the mean values of the activity of GPX among the seven groups ( $F = 118.661$ ,  $P < 0.00001$ ). Patients of Group III and Group VI are having statistically lower and higher mean values respectively of GPX, in comparison with the mean values of GPX of the other five groups.

## Discussion

Free radicals attack biomolecules in leprosy-affected persons. Free radical attack on polyunsaturated fatty acids (PUFA) resulting in the formation of a substance called malondialdehyde. In this study plasma malondialdehyde level was used as a marker for free radical production (17). We found increased plasma malondialdehyde levels in leprosy patients, especially in MB type of leprosy patients, confirming the involvement of excess free radical and oxidative stress. Those who were supplemented with antioxidant vitamin E showed a time- and dose- dependent attenuation in the level of lipid peroxidation (LPO). Our results are comparable with the general decrease in the antioxidant status in patients and confirm the need of exogenous supplementation of antioxidants, in coadministration with MDT. On exogenous supplementation with vitamin E we noticed a significant rise in vitamin E status and reactivation of the enzymatic antioxidant system.

The development of any bacterial disease involves a complex interaction between the pathogen and the host. This is particularly true of an obligate intracellular parasite like *M. leprae*, which seems to be a highly conservative type of pathogen in its intracellular attack to free radicals. Reports on the role of reactive oxygen intermediates in relation to *M. leprae* infections are sparse, and the topic needs to be studied further (18). One of the most important environmental factors that influence etiology of leprosy is nutrition (19); it is also recognized that nutrition in turn interacts strongly with a number of other environmental factors. Malnutrition increases the susceptibility to infection while infection adversely affects the nutritional status. Malnutrition coexists with a number of other factors which are likely to aggravate infection. One such factor is dietary antioxidant status. It is important to determine the extent to which the antioxidant status contributes to high rates of infection in poor communities. Among the malnourished, the incidence of infection exacerbations is high (20). The role of vitamin C, a water soluble antioxidant, in inhibiting the proliferation of *M. leprae* in the foot pads of mice has already been reported (21). Vitamin E a nonenzymatic, lipid soluble, immuno-enhancing antioxidant and an important free radical scavenger (22) is used in this study. Experimental studies on murine leprosy reveal the possible relationship between the cell wall integrity, components release and role of vitamin E in maintaining the lysosome architecture (23). There are reports supporting the possible effect of dapsona in inhibiting the oxygen intermediates, but dapsona-induced methemoglobinemia and methemoglobin can also produce free radicals (24). Some of the antioxidant enzymes like SOD possess Zn(zinc) in their active sites and zinc deficiency is already established in leprosy (25). Measurement of antioxidants provides evidence of susceptibility to free radical reactions, molecular damage (25), biochemical changes and involvement of internal organs. Such assays are likely to be of great value in assessing the free radical-mediated damage in leprosy patients under anti-leprosy treatment (26). Nutritional rehabilitation by way of exogenous supplementation of antioxidants will be an added advantage in the management in leprosy (27). Antileprosy chemotherapy should include not only the relatively rapid eradication of the vast majority of the viable bacilli but also retain the antioxidant status in affected individuals (28). From the public health point of view, antioxidant supplementation coupled with MDT (29) programs will give better results and maximum benefit to the patients, and it is an extremely important exercise to be undertaken in the chemotherapy of leprosy (30).

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## W.H. Miller

Voyageur Militaire Willie Herman Miller, Sr., was initiated into La Societe des Quarante Hommes et Huit Chevaux on February 23, 1991.

Voyageur Militaire Miller has served Acadia Voiture Locale 1351 as Chef de Train, Chef de Gare for eight years, and as Chairman of the Cajun Wreck for nine years. He has also served Grande Voiture de la Louisianne as Grand Commis Voyageur, Grand Chef de Train, and Grand Chef de Gare.

Miller has served Voiture Nationale as Alternate Cheminot National, Cheminot National, Disaster Relief Committeeman, and for two and one-half years as Special Awards Committeeman.

Miller has been Chef de Gare of his Voiture Locale 10 years and has served 9 years as coordinator of the Cajun Wreck.

He climbed the ranks in the American Legion, serving as Post Commander 4 years, 2 years as District Vice Commander, 1 year as District Commander, and 1 year as Department Executive Committeeman. He is currently serving as Post Membership Chairman. Has been on the St Martin Honor Guard 10 years and is in his third year as Captain.

Miller served in the Navy during the Vietnam era.

He is married to the former Dorothy Anderson, who is a Past Department President of the American Legion Auxiliary, Department of Louisiana. Both Miller, who is known as "Red", and his wife, who is known as "Dot", have belonged to the Legion family for 21 years.



## *International Recognition*

On September 16, 2002, Mary Ruth Daigle, was presented an award by José Ramirez, IDEA Coordinator for the U.S., on behalf of IDEA. Mrs Daigle was recognized by IDEA with the "Fighting Spirit" award for people who have worked to eliminate the stigma associated with Hansen's disease. Mr. Ramirez also presented her with a plaque for "Women of achievement" from the National Women's Hall of Fame at Seneca Falls, New York.

Mrs. Daigle was recognized with these awards at the first International Conference on Women Affected by Hansen's Disease, titled "I Will Walk With You", held at the Women's Rights National Historical Park at Seneca Falls on June 11-16, 2002.

During her Keynote Address at the conference, Magdalena Ramirez, Social Worker at the Houston VA Hospital and 2002 Texas Social Worker of the Year, acknowledged Mrs. Daigle as one of two Hispanic women from Texas diagnosed with Hansen's disease who served as her role models. We all congratulate Mary Ruth !



*Mary Ruth Daigle accepting the Award from José Ramirez, Jr.*



December 11, 20002

To: Carville Star Subscription Holders

I am glad to announce that after a short absence The Star is up and running again. For those of you that did not know about the changes at The Star let me bring you up to date.

The Star Office has moved to a smaller office and will now move into the electronic age. It will be online at [fortyandeight.org](http://fortyandeight.org) and will still be printed and sent to all subscription holders. The Star will be printed in Baton Rouge, Louisiana by Franklin Press and they will be distributed the same as the Forty and Eighter Magazine.

You are receiving this letter because you are a current subscription holder. You can download or read The Star online, however, you will need the user name and password for this year. The user-name is *carville* and the password is *star*. This will change each year and you will need to keep your subscription updated. The link can be found on the home page, that address is [www.fortyandeight.org](http://www.fortyandeight.org).

This means that Emanuel Faria, the Editor, and Bill Kikuchi, the Assistant Editor, will still be doing their jobs, however, they will not be printing the magazine. Voiture Nationale will maintain the subscription list in Indianapolis.

The biggest benefit from the down sizing the office space is, as you can see, the savings. The equipment has been disposed of already and the "Equipment and Maintenance Fund" will be changed to the "Maintenance Fund".

Basically The Star continues to be the voice of Carville and still needs your support. I ask that you continue to support the program by keeping your subscription and buying the countries, keep sending donations to the "Maintenance Fund".

Sincerely,



David R. Rabius  
Correspondant National

DRR/ep

## SOURCES OF HD TREATMENT IN THE UNITED STATES

THE NATIONAL HANSEN'S DISEASE PROGRAMS (NHDP) provides HD care to persons in the United States at 1770 Physicians Park Drive, Baton Rouge, LA 70816 and through the Ambulatory Care Program, which includes the following Outpatient HD Clinics:

### NATIONAL AMBULATORY HANSEN'S DISEASE PROGRAM

AREA	FACILITY	ADDRESS	PHYS/NURSE	APPOINTMENT
<b>BOSTON</b>	Lahey Medical Center	41 Mall Rd. Burlington, MA 01805	Samuel Moschella, MD Stephanie Burns, RN	781-744-5670
<u><b>CALIFORNIA</b></u> LOS ANGELES	LAC, USC Medical Center Attn: Section of Dermatology Room 8440	1200 North State St. Los Angeles, CA 90033	Thomas Rea, MD Helen Mora, RN Robert Jersey, OT	323-226-5240
MARTINEZ	Contra Costa Regional Medical Center Outpatient Clinic	2500 Alhambra Drive Martinez, CA 94553	Sutherland/Saffier, MDs Carol James, RN	925-370-5270 1-800-495-8885 (In state only)
SAN DIEGO	North Central Public Health Center	2440 Grand Avenue San Diego, CA 92109	D. A. Lopez, MD Carmen Rodriguez, RN	858-490-4400
<b>CHICAGO</b>	University of Illinois College of Medicine	Department of Dermatology, (MC 624) 808 S. Wood Street, RM 376 CME Chicago, IL 60612	Carlotta Hill, MD Norma Chelseth, RN	312-996-0734
<b>MIAMI</b>	Jackson Memorial Hospital	Ambulatory Care Center 1611 N.W. 12 <sup>th</sup> Avenue Miami, FL 33136	Anne Burdick, MD Gloria Ingle, RN	305-585-2600
<b>NEW YORK</b>	Bellevue Hospital Center Department of Dermatology Room 17-N-7	462 First Avenue New York, NY 10016	William Levis, MD Aloys Cabrera, RN Louis Iannuzzi, PT, C.Ped	212-562-6096
<b>PHOENIX</b>	Maricopa County Health Dept.	1825 East Roosevelt Street Phoenix, AZ 85006	Ronald Pust, MD Bill Cooper, RN	602-372-6661
<b>PUERTO RICO</b>	University of Puerto Rico Medical School	Department of Dermatology P. O. Box 365067 San Juan, PR 00936-5067	Pablo Almodovar, MD Sonia Santos-Exposito, RN	787-765-7950
<b>SEATTLE</b>	Harborview Medical Center	2 West Clinic - 359930 325 9 <sup>th</sup> Avenue Seattle, WA 98104	James P. Harnisch, MD Rebecca Finch, RN Tom McClure, PT, CH	206-731-5100
<u><b>TEXAS</b></u> DALLAS	Dallas County Health Department	2377 N. Stemmons Freeway, Ste. 522 Dallas, TX 75207-2710	Jack Cohen, DO Nancy Bernstein, RN	214-819-2010
<b>HOUSTON</b>	Houston Health & Human Services Dept.	1809 North Main Houston, TX 77009	Terry Williams, MD Eileen Walton, RN	713-504-0256
SAN ANTONIO	Texas Center for Infectious Disease	2303 S. E. Military Drive San Antonio, TX 78223	Robert N. Longfield, MD Debbie Mata, RN	210-534-8857
HARLINGEN	South Texas Health Care Center OPCL	1301 Rangerville Road Harlingen, TX 78550	Richard Wing, MD San Juana Thompson, RN	956-423-3420 ext. 351

<p><b>Other Sources:</b> State of Hawaii Department of Health 3650 Maunalei Ave., Suite 205 Honolulu, HI 96816 Phone: 808-733-9831</p>	<p>Mike Maruyama, MPH, Branch Chief Barbara Yoshioka, R.N. Program Manager Fax: 808-733-9836</p>
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**FOR MORE INFORMATION:** Call the NHDP at **1-800-642-2477** or fax: (225) 756-3760  
Email: [MTemplet@hrs.gov](mailto:MTemplet@hrs.gov)

# The Star

PO BOX 325  
POINT CLAIR BR  
CARVILLE, LA 70721  
carvillestar@aol.com

Phone: 225-642-5559 Fax: 225-642-9764

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## FACTS ABOUT HANSEN'S DISEASE

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### What is (HD)?

Hansen's disease, erroneously associated with biblical leprosy, is a complex infectious disease which, although recognized for more than two thousand years and found to be caused by a bacterium over a century ago, is not completely understood. Dr Gerhard Armauer Hansen, Norwegian scientist, first discovered the HD bacillus in 1873. Considerable progress has been made during the last 40 years, so that today we can treat the majority of cases without undue difficulty and counteract most of the fears generated by the folklore surrounding this disease.

HD is essentially a disease of the peripheral nerves, but it also affects the skin and sometimes other tissues, notably the eye, the mucosa of the upper respiratory tract, muscles, bones and testes.

There are both localized and disseminated forms of HD. If left untreated, HD causes nerve damage, which can result in loss of muscle control and crippling of hands and feet. Eye involvement can result in blindness.

### Where is HD Found

In 1994 the World Health Organization estimated that there were 2.4 million cases of HD worldwide with 1.7 million cases registered on treatment. The estimates for 1985 were 10 - 12 million and 5.4 million respectively. According to these estimates, in 1994, 70% of those who should be on treatment are now being treated. In 1992 there were 690,000 new cases reported and in 1993, 591,000 cases. There are also an estimated 2 - 3 million cases who have completed treatment but who still have residual disabilities who are not included in the above 1994 totals. The largest numbers of Hansen's disease patients continue to be in Southeast Asia and Central Africa with smaller numbers in South and Central America. The largest number of patients in the Western Hemisphere are in Brazil.

In the United States there are approximately 6,500 cases on the registry which includes all cases reported since the registry began and still living. The number of cases with active disease and requiring drug treatment is approximately 600. There are 200 - 250 new cases reported to

the registry annually with about 175 of these being new cases diagnosed for the first time. The largest number of cases in the US are in California, Texas, Hawaii, Louisiana, Florida, New York, and Puerto Rico. There are still approximately 150 cases at the Gillis W Long Hansen's Disease Center at Carville, LA; the only institution in the US exclusively devoted to Hansen's disease. The center functions as a referral and consulting center with related research and training activities. Most patients in the US are treated under US Public Health Service grants at clinics in major cities or by private physicians. (See inside back page for listing of clinics.)

### How Does HD Spread?

While this aspect of the disease remains a medical mystery, the most commonly accepted theory is that it is transmitted by way of the respiratory tract, and abraded skin. The degree of susceptibility of the person, the extent of exposure, and environmental conditions are among factors probably of great importance in transmission. Most specialists agree that 90% or more of the world's population have a natural immunity to the disease. Persons working with HD contract the disease only rarely. Cases of HD which respond satisfactorily to treatment become noninfectious within a short time.

### How is HD Treated?

Although the sulfone drugs, introduced at Carville in 1941, continue to be an important weapon against the Hansen bacillus the rising incidence of sulfone resistant disease necessitates treating all patients with more than one drug. Usually rifampin and sometimes clofazimine or ethionamide are given in addition to dapsone. Treatment rapidly renders the disease noncommunicable by killing nearly all the bacilli and these dead bacilli are then cleared from the body within a variable number of years.



Gillis W Long Center

## GET TO KNOW THE FORTY & EIGHT



The Forty & Eight, an honor society of legionnaires created in 1920 and *The Star's* primary funding organization, draws its origin from World War I. Millions of American soldiers in France were transported to the front in narrow French box-cars, called "Voitures," which would only hold 40 men or 8 horses. Remembering the close brotherhood of those box-car days, La Societe des Quarante Hommes et Huit Chevaux

(The Society of 40 men and 8 Horses) was formed and local Voitures began organizing as outstanding Legionnaires were invited into membership. Membership is still by invitation only.

Dedicated to the needs of their fellowman, the Forty & Eight raises funds and support not only *The Star*, but funds a national nursing scholarship program, various child welfare programs, provides aid to veterans and continues to promote Americanism at both local and national levels.