

JORNAL DO  
Morhan

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Newsletter of the Movement for the Reintegration of People Affected By Hansen's Disease – Brazil

Issue 30

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## **MUNICIPALIZATION**

**A headway for the elimination of Hansen's  
Disease**

# EDITORIAL

By ARTUR CUSTÓDIO M. DE SOUZA – National Coordination – MORHAN

## Dear subscribers, friends and activists of MORHAN

**D**uring the process of expansion, formation, and when necessary even exclusion of some branches we are implementing at MORHAN, we have learned a lot of things. Maybe the most important of them is the commitment we have with the Brazilian society to build citizenship and a collective and fair health system.

We have been using all we can to try to mobilize the community; such as the radio, the internet, newspapers, leaflets, the telephone (Telehansen®), that is all the available means we can use to gather around our cause.

Not long ago, one of our friends from the city of Manaus, emailed me the following story by an unknown author:

### *“Starfish*

*Once upon a time, there was a writer who lived in a quiet beach close to a fishermen village. Every morning he would walk along the shore to get inspiration, and in the afternoon he would stay at home and write. One day, while walking on the beach, he saw a silhouette that seemed to dance. As he approached it he realised it was a young man picking up starfish on the sand and throwing them back into the ocean, one by one.*

*‘Why are you doing that?’ –the writer asked.*

*‘Don’t you see!’ – explained the young man – ‘The tide is going down and the sun is shining high. They are going to die if they are left here on the sand.’*

*‘Young man, there are thousands of miles of beach all over the world, and millions of starfish scattered along the beaches. What difference can you make by throwing a few back into the ocean? Most of them are going to die anyway.’*

*The young man picked one more starfish up on the beach, threw it back into the ocean and looked back at the writer.*

*‘For that one I did make a difference.’ That night the writer was not able to write, nor was he able to sleep.*

*The next morning, back to the beach, he went looking for the young man, joined him, and together they began throwing starfish back into the ocean.”*

This text is very much like the reality we experience in our daily routine in the Brazilian social movement. Dear friends and activists of MORHAN, like that young man we are teaching those who write the story of the world how to make a difference.

Many starfish hope to be saved by us. And we can make our contribution by building the fair society we hope for. That is the difference we can make.

# COMSAÚDE CELEBRATES 30 YEARS OF EXISTENCE

Based on a report by Eduardo Manzano, coordinator of Comsaúde.

Comsaúde, a non-profitable, non-governmental organization, dedicated to carrying out programs in areas such as Health, Education and Community Improvement, is celebrating its 30<sup>th</sup> anniversary in Porto Nacional.

The history of Comsaúde began when a group of young health professionals, graduated from the University of São Paulo (USP), decided to start working as a team bound by the ideal of an integrated medicine and assessing their profession as a means of human development. It was then, in 1968, that they decided to accept the challenge of working in the recently built Unidade Mista de Porto Nacional. At the time the city was one of the most important cities in the North of the state of Goiás, it had about 18.000 population (70% in the rural area and 30% in the city area). The Tocantins River was a barrier that prevented the access to Belém-Brasília Road which represented the axis of development and also connected the Northern part of the state to its capital, Goiânia.

In its early years, the organization took part in programs aimed at

improvements on popular housing; job oriented courses, communication and support to arts and crafts and popular culture, as well as programs against verminosis and malnutrition. All this effort lead to the formation of community centers in neighborhoods in the outskirts of town, a craftsmen association, a rural workers union, hence Comsaúde began to work providing support and assistance.

Nowadays, Comsaúde has a non-profitable hospital with 38 beds and a ward, a Family Farm School with 180 students and a Nutritional Education and Recovery Center for 25 malnourished children, along with programs against Hansen's Disease, phitotherapy and cultural support, through the CRIP (Center for Popular Image Reference) department. Comsaúde also supports amateur theater groups and folklore events, and also is one of the organizations involved the Forum for Rural Reforms of the State of Tocantins.

## **MULTIPLE PROGRAMS REMIND COMSAÚDE'S HISTORY**

A meeting held on July 10<sup>th</sup>, anniversary of Comsaúde's foundation, to celebrate its 30 years of history along with a seminar about "Solidarity" gathering partner organizations and

support groups. The celebrations include monthly seminars on different subjects, related to Comsaúde's projects and departments, along with a week dedicated to culture.

With this program the organization intends to evaluate and restructure its goals and programs with the purpose of putting Comsaúde to work with today's popular movement, and the needs of the communities in today's world. For that purpose, Comsaúde needs all the organizations and people that fight for citizenship and for the construction of a more fair and fraternal society to participate in is this programming.

## **WORK WITH HANSEN'S DISEASE BEGAN IN 1988**

Comsaúde began working against Hansen's Disease in 1988, when the Constitution was enacted. The state of Tocantins was created in that year and the first government took the opportunity and sent away the active members of the opposing parties by transferring the Regional Hospital employees who belonged or were connected to Comsaúde's work to Goiás. That means that almost the whole group that worked with Transmittable Diseases in the State was transferred.

Health Department employees who were familiar with the work carried out by that team in Porto Nacional, and were concerned about the follow up on the Hansen's Disease patients, put this group in contact with the non-profitable organization AIFO (Associazione Italiana Amici di Raoul Folleareau). This organization provided funds for the maintenance of the program started by Comsaúde. A Project Against of Hansen's Disease was then designed with the City

Government in a Health Station in the district of Jardim Brasília, where the necessary conditions of medical assistance, physiotherapy and nursing where made available. That group later returned to their state and Comsaúde made a pact to maintain a service of regional reference that is kept until today.

A seminar on Hansen's Disease was held in February with the presence of the coordinator of AIFO in Brazil at the time, Giovanni

Gazelli, and of Artur Custódio de Souza, national coordinator of MORHAN. At this meeting, it was decided that a group of volunteers that belong to Comsaúde's program against Hansen's Disease would be responsible for representing MORHAN. They will organize the fight for the elimination of Hansen's Disease, and the stigma of the disease in that region, including the representation in the State Council of Health.

#### HANSEN'S DISEASE IS THEME OF A "REPENTE"

In the closing ceremony of the Hansen's Disease Course for Health Agents organized by CONASEMS' Task Force—of which MORHAN takes part, by the Secretariat of Health of Sobral, and with the support of MORHAN Sobral and MORHAN Maracanaú, Health Agent Francisco Pedro da Silva surprised us by reciting the following "Repente"\*:

*Good afternoon everybody  
Here I talk in poetry  
About a problem  
That doesn't make me happy  
The problem I'll talk about  
Is this so called Hansen's  
Disease*

*I know it doesn't bring happiness  
Sometimes it leaves a defect  
There are worst things  
That you can fix  
Creating Awareness  
Ending prejudice*

*And be it anyone  
Who takes culture seriously  
The person keeps to himself  
Not wanting to go out  
This has once been bad  
But today there is cure*

*If you are being treated  
You should only cheer up*

*The danger is over  
You can even hug  
This person is just normal  
You can even go on dates*

*We the Agents  
Please wake up  
Work with people  
Even if they are no saints  
Try to make contact  
Look for lesions*

*If you then find any lesion  
Do what is left  
Invite this person  
To a talk with one who knows  
For this talk  
With something sharp  
Go ahead and do the test*

*And in case you do contact  
This lesion at this point  
You won't think twice  
Or refrain from thinking*

*Talk to him  
Show him the way*

*Maybe I can't handle that  
I know it is not a disability  
This disease can be cured  
'Cause for all there is a way  
But the only thing there can't be  
Is this thing called prejudice*

*I'll end this story of mine  
In a way you won't forget  
We are all great agents  
We all must have confidence  
Do a good job  
And stay on the look out*

*On behalf of all the group  
I have told you all we did  
We have studied our book  
And repeated it all again  
So these are the verses from  
Your poet who is no one else but  
me*

\*Translator's note: Repente is a special kind of improvised oral poetry, part of Brazilian culture and typical of the northeastern part of Brazil. Its main characteristic is the metric and rhythm, which makes it, sound as you were singing, this effect can not be translated into English.

# AIFO

## AN ESSENTIAL PARTNERSHIP

The National Coordinator of AIFO – Associazione Italiana Amici di Raol Follereau, Giovanni Gazzoli, bids farewell to Brazil on his way back to his native country, but leaves behind a solid work that will be carried on by the new coordinator, nurse Deolinda Bittencourt de Santana. The partnership with MORHAN has been effective for 10 years and has translated into 20 projects aimed at Hansen's Disease.

### **What is AIFO?**

The AIFO is a non-profitable, non-governmental organization which main purpose is to fight against any kind of discrimination. It was created in 1961 and has been working in Brazil ever since. The Associazione Italiana Amici di Raol Follereau has 54 registered groups in 54 cities in Italy, which work promoting awareness to the problem of Hansen's Disease. In Italy the disease has been eliminated and the only registered cases are imported. AIFO work in 60 countries on 204 projects.

The non-governmental organization is named after Raoul Follereau, a French writer and journalist who died in 1977 and dedicated his life to people with Hansen's Disease. Although he was never a patient, he became aware of it on a trip to Africa, where he began his political battles with the institutions.

### **AIFO IN BRAZIL**

Working as coordinator of AIFO in Brazil since 1994, Giovanni Gazzoli explains that his job consists of giving technical and managerial support by supervising specific projects, trying to understand the reality of the area and link the people responsible for this projects to public institutions, therefore enabling the interchange between them. "The main role of AIFO's coordination is to find the best possible way to appropriate the organization funds, donated by the Italian people."

AIFO has 20 projects in partnerships in Brazil all aimed at expediting the elimination of Hansen's Disease.

Besides the matter of treatment and decentralization of attention, physical and social rehabilitation activities are a priority. We would like to call special attention to five projects that are being carried out together with the Secretariats of Health of Goiás, Acre, Pará, Bahia and Distrito Federal. Along with the national coordination of MORHAN, AIFO has been providing funds for activities such as organizing and forming branches, support to MORHAN's Newsletter, besides the participation of MORHAN's National coordinator, Artur Custódio de Souza, in the AIFO Assistance Committee elected in the last meeting. AIFO also stands out for the support it gives to other people's movement, Comsaúde of Porto Nacional, recently affiliated to National MORHAN, and religious congregations. In addition to that, AIFO also maintains 11 projects focused on needy children in schools and daycare centers; projects of public health for Yanomani Indians in the Amazon; an educational project in the settlements of the Landless Worker's Movement in the states of São Paulo; and what is called R.B.C. (Community Based Rehabilitation).

Evaluating the time as head of AIFO in Brazil, Giovanni Gazzoli says there was a great improvement in the education of professionals and information about early symptoms. "What we still need to do is fight against prejudice and for care decentralization", he adds.

### **FUTURE PROJECTS**

According to Giovanni Gazzoli, AIFO's future projects include financing the technical supervision of the central state coordination teams and training of professionals to work in City Health Centers.

They also intend to expand the communication network of the projects to increase the interchange of experiences and also to identify new educational methods. The coordination of AIFO also wants to improve the interchange between Brazilian projects and AIFO groups in Italy.

## **BRANCHES UPDATED**

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### **Belfort Roxo honors Gérson Pereira in new Branch**

The Municipality of Belfort Roxo, in an area called Baixada Fluminense in Rio de Janeiro is opening the new Dr Gérson Fernandes Mendes Pereira Branch, as a tribute to the coordinator of the dermatology technical area the Ministry of Health. Gérson, who's been actively working with MORHAN since 1985, is a 37 year old sanitation doctor from Piauí, specialized in epidemiology and Hansen's Disease, and has a Master's degree in Hansen's Disease.

Touched by the tribute he responded by saying that MORHAN is very important in the health area. The new Branch will be coordinated by José Guilherme Alves Pereira, who will work with 18 volunteers he drafted, and will be supported by several enterprises.

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### **São João de Meriti motivated for campaign**

MORHAN (Alice Tibiriçá Branch) in São João de Meriti (RJ) is going to have another meeting with the Municipal Secretary of Health, João Ferreira Neto, to discuss the creation of a strategic group to help draw up the municipal campaign to expedite Hansen's Disease elimination.

The secretary who named a representative to take part in the project approved the campaign. Also involved in the project are the Municipal Secretary of Work and Social Promotion, Municipal Secretary of Education, the National Health Foundation and representatives of the population organized as the 31<sup>st</sup> Scout Group M. Rondon, the Associação Batista Meritiense, Aspas and Núcleo dos Desbravadores. The goal is to start the campaign in November. MORHAN representative Marcelo Vieira should meet with the Mayor of São João de Meriti, Antônio de Carvalho, to obtain support for the campaign.

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### **MORHAN-Limeira & Aldeia's Theater**

The Limeira/Aldeia Branch has created a Theater Group opened with two successful presentations, in both Health Centers in the outskirts of town. In addition to that, a Health Humanization Seminar held by the Municipal Secretary of Health. Vicente Pironti, Executive Director of the group told us that the Theater Group would be soon performing for the public network of Education and Health.

MORHAN –Limeira & Aldeia's Theater Group is formed by volunteers Rogério Barrel (Art Director), Verônica Miqueli Giuliani and Daniele Alessandra Chinellato (creators of the group), Vicente Pironti (Executive Producer), and artists Wagner Ricardo Fernandes, Mariana Menconi Chinellato, Valéria Miqueli Giuliani and Amanda Penedo Barros. The group also has the support of Aldeia's Group Pro Cultural Movement and the Municipal Secretary of Health of the city of Limeira.

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### **MORHAN-DF LAUNCHES PROGRAM**

Federal District's (DF) MORHAN is setting up a program called "Morhanzinho fraterno" (Fraternal Little MORHAN). Aimed at children and teenagers, the program intends to discuss sexually transmitted diseases (STD), drugs and adolescent pregnancy. Adeuzinha Dias, coordinator of the branch, explains that the project will be carried out with residents of Super Quadra Norte 108 (SQN 108), an area of Brasilia-DF, through lectures, folders and videos. The first meeting will be held in August.

And we would like to inform that the DF Branch is now located at a new address: SCLN 108 Bloco C, sala 92, the area code is still the same (61) 340-4137.



based on full attention under the responsibility of the city. "Hansen's Disease, as well as any other endemic disease, even with the support of and demands from the State and from the Ministry of Health, can only be tackled if a partnership between the city and the people is developed for the construction of the health system", he adds.

There was no MORHAN branch in Palmas, but this event moved people, Neilton says. "People started to volunteer, forming a group that I think may be a good connection for MORHAN in the region, helping build a supra partisan movement and a collective health system compromised with building, strengthening and maintaining. MORHAN's role is bigger than mere social mobilization. In close relation with the municipal Secretaries and the Ministry of Health, it provides the non-governmental element and the voice of the community, being one of the main forces", he added.

The Ministry passes on to the people the lowest per capita funds in the country, about US\$3,00 to US\$3,50 of the PAB (Assistance Base Value). Despite all the claims for improvements, the Secretary of Health believes that the support should come from the people, therefore we should develop a positive dependence with them to help build the system.

According to Neilton, what is special about the city of Palmas is that it is a new and jolly city without imperfections or mistakes to be corrected.

The discussions during the meeting were about the basic concepts of totality and universality, "SUS (Single Health System) is for everybody". Quality of life was discussed from a perspective of fighting capability, according to Neilton,

fighting capability of the organism of child, pregnant woman or elderly person to react to a bacteria attack. And capability of the social individual and of the municipality to fight against the factors that prevent its, social, physical and mental well being.

Another concept discussed is that of interdependence. The action against Hansen's disease is treated with the school, the church, the doctors, the associations, and the media. The problem with this disease is not only treatment, fast diagnosis, or follow up, but also the stigma, the relationship with their families, the neighbor's family, and that of his family and the society. A successful experiment that can be found in Palmas and which reflects this reality is the "Friendly Neighborhood Project."

Due to the high rate of migration, with a growing rate of 28.7% a year, when a new family moves into town, the Secretary of Health motivates people to inform through the "Alo Saúde" (Health Call). On the same day a Health Agent is sent to welcome the family into town, informing them about the health, water and garbage systems (130 agents for each family, turning each citizen of Palmas into a Health Agent).

This Information system was only implemented in Palmas in 1977, when 246 new cases of Hansen's Disease were registered. In 1998, 276 more cases were registered, and in the first five months of 99, 165 more. This increase shows the uncovering of hidden cases of the disease, through a collective search, tracking the infected person and curing him/her in a way he/she can talk about.

#### **WOULD YOU SAY I HAD HANSEN'S DISEASE?**

This question is part of an advertising campaign launched in Palmas aiming at telling people about the disease and changing its image, destroying myths and protecting the community.

The perspective of a specialized treatment like the vertical plan once implemented by the Ministry of Health. In that plan the Ministry trained the municipality, which in turn chose a unit to serve as reference. When the patient didn't show up for treatment his form was filed and a report closed the issue

The program cannot be organized with only one municipality, so from Palmas it has spread over to 139 other municipalities in the state of Tocantins, training and improving human resources, not centered on the doctor anymore, since many cities don't even have a doctor. Now, the community agents inform about suspect cases, and every health center is being prepared to make simple diagnosis. The next step is strengthening the program, spreading towards the borders of the South Pará and South Piauí States.

#### **THE GOAL OF THE MINISTRY IS TO REDUCE THE NUMBER OF CASES**

According to the coordinator of the dermatology technical area of the Ministry of Health, Gerson Fernando Mendes Pereira, the Northern Region has 15 patients for each 10,000 population, while Brazil's average is of 5 patients for 10,000. The discrepancy can also be noticed when you talk about prevalence, which in Brazil is of 3 for 10,000 population and in the Northern Region it goes up to 8 for 10,000. In the state of Amazonas it rises to 17 for 10,000 population.

It gets even more complicated when you consider how low the coverage of the program is, how difficult it is to get to the area, and how few means of transportation are available.

By means of a decentralization of the actions taken for the control of Hansen's Disease we hope to reduce prevalence, detection and abandonment rates. Representatives of the Northeastern (Bahia) and West-Central Regions were also present at the meeting.

#### **WHO ADOPTS STRATEGY PROPOSED BY TASK FORCE**

For Vera Andrade, representative of Conasems Task Force, the meeting at Palmas was the start up of the decentralization with assistance quality. "It was a success. The presence of the WHO proved that the strategy of

Conasems Task Force is the more adequate to speed up the elimination of Hansen's Disease as a public health problem." Vera recalled that from March to June the municipality of Palmas has expanded the assistance from 5 to 19 health units.

She also told us that the Task Force technicians should take part in a meeting in Geneva, where they will discuss the use of this strategy in highly endemic countries like China and India.

According to Vera, the Task Force is a catalyzer that is various partners get together but each one does his part, starting with the municipal manager. "All sectors are represented in the group: the community through MORHAN, Conasems and the WHO," she explained.

She says that the strategy of the Task Force consists of

"generating some chemistry" between the various procedures: increasing the users access to assistance, qualifying health professionals, distributing medicine and motivating people to make them believe that Hansen's Disease is a curable disease. "The individual must be diagnosed in the early stages of the disease, when there is still no handicap or visible change in his physical appearance," she states. As stated by Vera, national TELEHANSEN has been one way to access how effective the strategy is. "It is not only one more number you can call toll free, but people can call and tell us how well they were treated, if there was medicine available, or ask us to which units they should go. It's a line aimed at improving treatment."

### **BULLETIN OF THE 1<sup>st</sup> HEALTH MEETING OF THE NORTHERN REGION**

#### **Municipalization: Headway Towards The Elimination Of Hansen's Disease**

In the first meeting of Managers for the Northern Region, held in the municipality of Palmas, capital of the state of Tocantins, from June 16 to 18, 1999, with the purpose of advancing on the decentralization of the treatment of Hansen's Disease, the consensus was that:

- Expediting the elimination of Hansen's Disease as a public health problem depends on a commitment by the municipal manager in assuring the access to and provision of quality assistance to Hansen's Disease patients.

As a result the main issues were agreed:

1. Signature of a technical cooperation agreement between CONASEMS, MS and WHO/PAHO to expedite the elimination of Hansen's Disease as a public health problem, according to CONASEMS Task Force (GTAEH) method; its strategy is the simultaneous implementation of:

- Decentralization of the MDT/WHO treatment to all sanitary units;
- Sustainable qualification of human resources in Hansen's Disease;
- Distribution of informative material about the Hansen's Disease cure.

2. Formal agreement between CONASEMS and Novartis Foundation to implement the strategies of the Task Force at a municipal level.

3. The Ministry of Health, through its technical area, shall stimulate and motivate non-governmental organizations (ONGs) that work with State HD Coordination to adopt the strategy proposed by CONASEMS Task Force.

Based on the peculiar reality of each area, we suggest that managers seek local, national, and international partners willing to support this strategy in a way that can make the acceleration of HD elimination a reality in the municipality as soon as possible.

Palmas, June 18, 1999

## Meeting of The National Coordination of MORHAN meets goals

The meeting of The National Coordination of MORHAN held from June 25 to 27, in Santa Teresa, Rio de Janeiro, lead the way to historical decisions as to ethnical questions in the Branches. With the participation of volunteers and of the movement's national coordination, some issues for the 1<sup>st</sup> Special Meeting were set up.

For two days we discussed MORHAN's National Policy, the reassessment of the Branches, the councils, the meeting at Salvador, the 1<sup>st</sup> Special Meeting, and MORHAN's Actions towards a unified health policy. The event was sponsored by the Ministry of Health that provided the tickets and funding for AIFO and Conasems.

### THE HANSEN'S DISEASE PROGRAM IS IMPROVING

The coordinator of the technical area of sanitary dermatology of the Secretary of Health, Gérson Fernandes Mendes Pereira, and highlighted MORHAN's initiative and of the dermatology area, which gave expressiveness to the movement of patients, followed until today by the health policy carried out in the Hansen's Disease area.

Gérson Pereira presented data about Hansen's Disease in Brazil in 1997 when 88.000 cases were registered. He says the numbers for 1988 must have been close to 67.000.

As for the new cases, Gerson says that for 1998 the new cases must amount to 49.000. He reports that there are 5 patients for each 10,000 population, while the World Health Organization defends that for a country to eliminate the disease this numbers should come down to one patient per 10,000 population.

As far as the other states are concerned the Ministry of Health points the Northern, Northeastern, and West-Central Regions as the ones with the largest number of cases of Hansen's Disease. A positive data about the Southern Region: the states of Santa Catarina and Rio Grande do Sul have already reached the goal of less than one patient per 10,000 population, that means that according to WHO standards they have eliminated the disease as a public health problem.

The Ministry of Health foresees that by the year 2000 we will be registering 3 cases per 10,000 population, which means that we still will not have completely eliminated the disease. However, Gérson defends that even *that* is a great accomplishment in a country where there used to be 17 patients per 10,000 in 1991.

He also points out that to reach the goal set by the WHO, of 1 patient per 10,000 population, all the cases should be diagnosed as early as possible, breaking the transmission chain of the disease. There is also a need for closer assistance to the patient in order to reduce the abandonment rate. "The strategy is to decentralize the actions of the Hansen's Disease control program as much as possible," he says.

### BRANCHES: HISTORIC DECISIONS ABOUT ETHICS

During the meeting of the National Coordination of MORHAN it was decided that the Itu branch will be closed, and that the people will be informed through announcement in a large newspaper. In addition to that, official correspondence will be sent to businesses and authorities that used to work with the Branch.

The net worth and bank account based on the by-laws. All decisions were approved by vote. The open voting session was held after the analysis of a report by the ethics commission who visited the branch with members of the national and legal counsel.

The inappropriate use of funds by its former director was a main factor, which led everyone to decide for the closing of the Branch.

Another branch that was subject to discussion was the Branch of Anápolis. It was visited by Adeusina Dias, responsible for the regional coordination, and she is writing a report to the National Coordination requesting a visit by the ethics commission and the legal counsel.

Another important decision is related to two "ghost branches". The National is going to supervise them and request documents so that they can fit in with MORHAN's policy or be closed like too.

The Branch located at São Luiz, Maranhão, from which the funds where stolen is being analyzed by the legal area and its director asked for their right to defend themselves.

Cristina Paineira, lawyer for MORHAN, considered the decisions about the Branches extremely important. "It was a breakthrough in the discussion of ethics in the Branches. We have made decisions that had never yet

been made in the history of MORHAN. People are satisfied and what happened is to remain in the memory of the movement, so that something like this will never happen again.”

Cristina listed the decisions: there will be supervision, documents will be requested from the branches and compliance to the rules and rendering of accounts to the National should be done.

Those who fail to render their accounts in time or even refuse to send them in will be secluded from MORHAN.

### **CONTROVERSIES VALUE DISCUSSION**

The 1<sup>st</sup> Special Meeting is scheduled for November 14, before that the regional meetings shall be scheduled. One of the matters at hand will be the discussion about whether or not to sell the real state where MORHAN's national headquarters is located, in São Bernardo, São Paulo. This matter is bound to raise a lot of controversy. The national coordinator of the movement, Artur Custódio, defended that in Brasilia there is enough foundation to create new headquarters. Antônio Borges, the Vice-coordinator, on the other hand opposes to the sale.

Another person opposed to the sale is Doctor Lúcio Luiz Souza. Artur Custódio presented yet another alternative: keeping the house and drawing a contract with a clause providing for possible future sale. This way, the building could be let out to a shoe repair cooperative, and the repairs and the tenant who lives there would pay for bills.

In the National Meeting of MORHAN's Coordination the proposal that each brand sends only one representative to the special meeting was also approved.

Novartis Foundation has offered to sponsor next years national meeting, when the agenda will be include Hansen's Disease X Leprosy; Colony hospitals, and the growth of the movement.



# Morhan

## Report

### **COMMITTEE IS TO REVIEW TECHNICAL RULES**

A technical-scientific committee to assist in the technical area of HD was created in a meeting held on June 23. The procedure was regulated through administrative act 485 of the Ministry of Health, from 4/19/99. The coordinator of the committee, Gérson Fernandes Mendes Pereira, explains that the first job to be carried out is a revision of the technical rules. “The most recent rules date from 1993 and must be updated.”

Tem other members form the committee: Artur Custódio de Souza (MORHAN), Euzenir Sarno (Fiocruz), Maria da Graça Cunha (AM), Maria Leite de Oliveira (UFRJ), Clóvis Lombardi (WHO/PAHO), Jair Ferreira (Federal University of Rio Grande do Sul), Antônio Lopes (Palavra e Ação—

Word and Action), Vera Lúcia Gomes de Andrade (Conasems), Dilton Opromolla (SP), Linda Lenhman (ALM).

### **FAILURE OF TELEPHONE COMPANY HINDERS TELEHANSEN®**

Cristina Pereira, Lawyer and legal counsel of MORHAN, started a procedure with the Attorney General of the Republic asking that it investigate with Anatel as to the inefficiency of Embratel.

This is due to a failure that occurred in the first week of July, which left TELEHANSEN® (0800-262001) out of order. The lawyer defends that the health assistance and public service was hindered, and that the damages can not be measured.

### **INTERNATIONAL SCIENTIFIC CONGRESS DISCUSSES HANSEN'S DISEASE IN MS**

The International Scientific Medical Congress-OMNIA 99 is to be held at São Julião Hospital, in Campo Grande (MS) from September 22 to 24. Among the scheduled events are the III International Medical Congress, the First Meeting of Engineering and Architecture, the I International Meeting of Agrarian

Sciences, and the IV Meeting of Hansen's Disease Surgeons.

On September 21 Hansen's Disease will be discussed in to conferences and a table d'hôte. The first one is “Rehabilitation in Hansen's Disease—a historic perspective”, with Professor Frank Duerksen. The second conference “The rehabilitation of feet with Hansen's Disease will be chaired by Professor H. Srinivasan. From the table d'hôte “ONG and Hansen's Disease rehabilitation” will take part Artur Custódio de Souza (MORHAN) e Antônio Lopes Filho (ALM), among other organizations such as AIFO and DAHW.

### **MORHAN WINS SEATS IN HEALTH COUNCIL**

It is a policy of MORHAN to take part in Health Councils. The National Coordinator, Artur Custódio de Souza, has had a seat in the National Health Council for the two terms.

The movement celebrated winning a seat in the Municipal Health Council of Niterói, Rio de Janeiro, during the III Health Conference after receiving the vote of over 700 delegates. The Forum also insured MORHAN's representation in the

State Health Council during the Health Conference of the State of Rio de Janeiro.

MORHAN (Alice Tibiriçá Branch) in São João de Meriti (RJ) won a seat at that city's Council of Health, having as its representative Marcelo Vieira.

The election was held on June 7, during the Municipal Forum of Health, and the decision was enacted in the Municipal Health Conference of São João de Meriti, on June 12.

Marcelo Vieira explains that when taking part in the Municipal Health Council of São João de Meriti, MORHAN will actively take part in MORHAN is sending a project on "Health and Education" to the National Health Foundation. It is true that this crucial factor for the construction of Brazilian people's health has lost strength. Health and Education are always relegated to a last plan in this government,

#### **FORUM GATHERS ENTITIES OF CARRIERS OF PATHOLOGIES AND DISABILITIES**

The Forum of National Entities of Carriers of Pathologies and Disabilities was held on July 7, in Brasília, in the Auditorium of GOB (Grande Oriente do Brasil).

Through the whole day the organization of the forum was discussed with its bylaws and formal legal structure.

Present at the forum were MORHAN, the Association of Families of Mental Patients (AFDM), Franco Basaglia Association, Brazilian Autism Association (ABRA), APCB, ADJ, Kidney Disease Federation of Brazil, Brazilian Hemophilia Federation, Federation of Down Syndrome Associations, Grupo pela Vida (SP) representing ONGs/Aids, National Organization of the

the discussion of the health policy for the city.

These are the members of the Council: MORHAN, Associação Batista Meritiense, Rotary Club, Casa da Cultura (Culture House), Reencontro, SUDMAN, 1<sup>st</sup> Baptist Church of Vilar dos Teles, Popular Entities Council (former ABM) and Aspas, these last two holding two seats each. MORHAN has also taken a permanent seat in the Municipal Health Forum.

#### **PARTNERSHIP WITH CONAM**

The Congress of the Federation of Residents Associations was held on July 3 to 6, in Goiânia, with the therefore "health education" end up being abandoned in two ways.

#### **CURITIBA AND THE DECENTRALIZATION OF HD**

The Municipal Secretary of Health of Curitiba has produced some material for the promotion of a positive image of Hansen's Disease; Disabled (ONDF), and Liver Transplanted Patients Association.

Many organizations that were not able to attend justified their absence. It was agreed that from now on the event would be called National Forum for the Rights of the Pathologies and Disabilities. The bylaws were then discussed.

The Forum was sponsored by MORHAN, Loja Estrela and Estrela do Oriente Fraternal Group. The next meeting is to be held on September 5, in Brasília.

#### **MORHAN GATHERS TECHNICAL ASSISTANCE**

On August 7 and 8, in Santa Teresa, Rio de Janeiro, The national Technical Assistance MORHAN's and the Formation Department, elected in the last National Meeting, met to discuss, among other things, a proposal of administrative act by the Ministry of Health. The Ministry of Health intention of issuing a new administrative act ruling on

presence of 1,000 delegates, occasion when Edmundo Ferreira Pontes was reelected president.

The managing director for the new administration, Carlos Martins, whose job it is to organize the community movement has been making contact with MORHAN. "We are looking for the best way to help them since Conam represents all organized communities in Brazil, through residents associations, and it is clear that MORHAN's volunteers are part of this groups, linking the community movement to the social one."

#### **HEALTH EDUCATION**

its signs, symptoms and TELEHANSEN@, to promote better information. The Secretary is now committed to setting up references in the public health network to treat the disease and start comprehensive training of health professionals, strengthening the decentralization.

Hansen's Disease control in Brazil was considered extremely important.

This tends to an urgent need of organization of the State and City Health Network.

Present to the meeting were: Dora Martins Cypreste (Social Worker), Luiza Claudia Bernardo Abreu (Occupational Therapist), Cristina Paineira Paschoa (Lawyer), Zilda Maria Borges (User), Luiz Augusto Costa de Oliveira (Sociologist), Luiz José da Silva(user), and Doctors Germano Traple, Eduardo Rabelo de Abreu, Rachel Tebaldi Tardin, and Lúcio Luiz de Souza. Artur Custódio de Souza, Márcio Menezes da Costa, Ivanir Gomes, Roseli Brum Martins, Leandro Molina and Marcelo Vieira represented the Executive Department.

# INTERVIEW

## **JOCÉLIO DRUMOND**

### **- CUT**

International Relations Director of the National Federation of Social Security Workers of CUT (Unified Workers' Central). Also represents CUT in the National Health Council. In the International area coordinates the Public Servants International in Brazil.

### **- BRAZIL**

In this interview Jocélio Drumond states his support to social movements, assimilating ideas from unions and helping organize common actions.

## **Unions can be powerful in supporting social movements**

Jocélio Drumond, International Relations Director of the National Federation of Social Security Workers of CUT (Unified Workers' Central) talks about how these partnerships can help improve quality of life.

### **MORHAN Newsletter (MN) – When did CUT and MORHAN first interact?**

**Jocélio Drumond (JD)** – Artur Custódio de Souza, National Coordinator of MORHAN, and also member of the National Health Council, was present at a seminar held by Public Servants International, a worldwide association. The debates were about what interests and actions the Unions, States, Councils and ONGs might have in common and how these institutions relate to each other.

### **MN – How do these social and workers movements relate?**

**JD** – What we can do is work together. MORHAN activists should get involved with their Union whenever possible. Showing them exactly what it is to be active in an ONG, what it is to fight against Hansen's Disease in Brazil, and the problems they face, so that a partnership can be established. On the other hand, the Union should become more concerned with the Health problems of the Brazilian people, with their quality of life. This combination of efforts is extremely positive, for the Union fortifies MORHAN's Fight, and MORHAN reinforces the citizenship concept that the UNION aims to improve.

### **MN – Can this partnership be straitened?**

**JD** – Unions can strongly support ONGs, especially those like MORHAN. With its structure, funds and influence it should forge partnerships to fight for better health conditions. And this partnership could develop into joint work.

MORHAN can help the Unions. For instance, who is going to fight for the rights of a Hansen's Disease patient fired from his/her job? It has to be the Union. And for that it has to be familiar with the problem and how to act upon it. Through this partnership, MORHAN can provide the information that the Union needs to fight for the patients rights. That has happened with Aids patients. Aids ONGs are frequently asking the Union to fight for the right of the patients whose rights have wronged.

The Union is elaborating a manual on how to plan actions to defend the disabled, in a partnership with the National Organization Entities of Carriers of Disabilities. The same can be done for the Hansen's Disease Patients.

The Councils of Health, CUT and MORHAN also share the fight for their ideas, sometimes similar ideas, expressed in forums such as National Health Conferences, and probably in the Cities and States too. That's another possible partnership: the Union could help decide what is essential to MORHAN, how to prevent Hansen's Disease, how to improve care to the patient, and how to guarantee his/her quality of life.

As MORHAN and the Union work together, MORHAN is teaching the Union how to better perform its tasks.

**MN – Does the Union have volunteers?**

**JD** - There are two kinds of Union leaders; the ones who are legally released from their jobs and maintain the wages to work in the Union; and the ones who are volunteers, most leaders are volunteers. The volunteers might, at most, receive part of their salaries for working full time at the Union. None of them are paid to work at the Union, what they restitution of their salaries. As for the ONGs it is even more difficult because the volunteer has to work for his living and still take part in the activities of the ONGs.

**MN – Is there prejudice in the Union?**

**JD** – Any illness seems charged with mystery, a certain prejudice and ignorance of those not familiar with the disease, either because they are not Health professionals, or never had a patient in the family. But prejudice is not only against Hansen’s Disease, but also against most pathologies, especially those which are not well known.

**MN – Does the union have any commitment with SUS, in its fights in the Heath area?**

**JD** – It is involved with SUS since both fight for quality health care for the people, or when a health center is to be closed to be turned into something more useful like a colony hospital. The Union is very fond of fights like that. However, many Union workers have some kind of private health plan, such as those who work in metallurgic, chemical and petroleum areas. Few workers use the free health system; only construction workers, and public sectors. The partnership may be effective not only in actions for quality care for the people, but also when it comes to health plans related to SUS.



**Sobral gathers patients and health professionals**

The 1<sup>st</sup> Meeting of Users and health Professionals for the elimination of Hansen’s Disease held in Sobral, in Ceára, on June 29, gathered around 300 people and had as a main subject the decentralization of care for the Hansen’s Disease patient. A MORHAN Branch will also be opened in the city.

The meeting validated the decision of expanding care to 24 health centers. Nowadays it is restricted to three places; Sobral Heath Center, the Family Health Team of Bairro Tamarindo, and Jaraíba district.

The Health Secretary of Sobral, Luiz Odorico de Andrade, emphasized the importance of the partnership with Conasems Task Force. Another important factor for the decentralization was the course for heath professionals (doctors and nurses) from the Family Health Program, who will work in the detection, direction and follow up of patients. The course took 12 hours, divided into 8 hours of theory, and four hours of ward practice and case discussion, 51 professionals were trained. There was another course on for Health Agents detection, direction and follow up of Hansen’s Disease cases.

Ivana Cristina de Holanda Cunha Barreto, infectologist of Sobral Health Department, told us that the meeting also improved the relationship of patients and health workers, and clears the stigma of prejudice. “Several people gave their testimony and said they are cured,” she said.

Francisca Marlene Souza Bezerra, a Health Department technician, who has been working in the Hansen’s Disease program since 1991, considered it an excellent meeting. “Patients had a chance to express their anxieties and opinions.” She is also organizing the formation of MORHAN-Sobral Branch, which already has 15 volunteers but is yet to elect its directors.

Antônia Mágila Rosa da Silva, nurse and volunteer who participated in the meeting, found the participation of the patients and professionals very interesting and hopes to organize a MORHAN Branch in the city of Santana do Maranhão.

## **SOBRAL IS A HIGHLY ENDEMIC AREA**

In 1997, the Coordination of Health Awareness of Sobral's Municipal Secretary of Health implemented the SINAM (Injury Information System). Since then, it has been updating and correcting information on the registered cases of Hansen's Disease in its database.

The data tells us that the detection of cases of Hansen's Disease in Sobral went from 9,5 per 10,000 population, in 1995 to 7 per 10,000, in 1998. The prevalence of the disease in the city in the same year was of 11,2 per 10,000 population, qualifying Sobral as a highly endemic region. The data also tell us that there has been a decrease in the number of cases qualified as a paucibacillary and tuberculoidis form and an increase of multibacillary cases. According to the secretariat's evaluation this is due to the fact that the classification of some cases done previously as tuberculoidis, even when showing more than five skin lesions and/or more than one affected nerve trunk. Since 1988 these cases were classified as multibacillary and treated with PQT/MB.

In 1995 more female cases were detected and in 1998 there were about the same number of male and female cases.

In the chart that follows are the epidemiological indexes for the annual evaluation of the Municipal Program of Hansen's Disease Control and Elimination. Its levels set this problem as one of the top priorities of the Health and Social Works Municipal Secretariat of Sobral.

## **DECENTRALIZATION OF CARE**

Until May 1999 the Hansen's Disease care service was located at Sobral's Health Center. At the time there were two nurses, each working 20 hours, and two doctors, each dedicating 4 hours a week to taking care of the HD cases. Since July one of the nurses has been dedicating 20 more hours to this service.

Today, in Sobral, there are 31 family health teams, distributed among 24 health units, equipped to diagnose and treat the cases detected in the first semester of 99. Since May 1999, to family health teams, called Jaibaras and Tamarindo, have been following up on the HD cases under its coverage area. The goal of the program is to decentralize care to all health units until September, aiming at detecting the new cases at early stages, reduce abandonment rate and consequences.



## **COMMUNITY RADIOS**

### **Information and audience guaranteed**

Cláudia Silveira

Press Assessor for MORHAN

There are over 800 community radio stations all over Rio de Janeiro State. This may lead us to a conclusion that is so clear that we frequently fail to see it: how important this so-called alternative means of communication really are.

In the last few months MORHAN has intensely invested in this media. This media, although looked despised by institutions and journalists alike, have a captive audience, faithful to its programming, and mainly participant. Many community radios still maintain a general commitment of "telling the listeners the truth", although many have escaped their original purpose. Their original purpose was, as the name says, to be done by and focus on the community with characteristics almost opposed to those of commercial radios.

The experiences have proved positive. Occasional interviews have already been incorporated into a kind of movement "calendar": there a days and times scheduled to talk about Hansen's Disease and matters related to it. An example? São João de Meriti's Branch, in Rio de Janeiro State, is almost a "registered customer" of Rádio Onda Livre FM. There isn't a single action that goes unmentioned

by the journalists-radio announcers-volunteers: pamphlet distribution, meetings and so on and so forth.

Let's stop and talk about the journalists-radio announcers before we give more examples. They are "the people" we should "form and inform". What do I mean by that? Well, it's quite simple. The movement doesn't need favors or charity from the press. But it does need to raise awareness, starting from the editing room itself. Capturing promotion opportunities, whether they be on a community radio or not, is easier if the other is involved. That's where the journalist and/or radio announcer becomes a volunteer and....we have a ball! We will have an ally as good as, or even better than the highest public health authority. And this is not an overstatement or figure of speech.

Rádio FM Vida, in Juazeiro do Norte, Ceará, maintains an open channel for the movement airing daily messages about the signals and symptoms of Hansen's Disease. MORHAN Gerais FM community radio has been utterly important in promoting activities and informing the public. Santo Inácio community radio, in the district of Andaraí, Rio de Janeiro, has opened its doors to MORHAN. What was supposed to be just an interview turned into an important ally: we will soon have our own airtime to talk about Hansen's Disease. And don't you think the audience is just as big as an egg, it's more the size of a watermelon: at least five districts, some among the most densely inhabited.

These are some of the numerous experiences that the community radios can provide. Imagine being able to stay on the air, nationwide, during TV prime time, which is too great an illusion. There is only one person I know who is always on Jornal Nacional: Fernando Henrique Cardoso, our president. Let's not discuss his merits, but let's get on the road and find a greater, more meaningful world than that which comes into our house every evening at dinner time.

## Step by step

### - **What is a community radio**

As the name says it is a radio "done by" and aimed at the community. According to a law to be passed by the Congress community radio broadcasting is FM radio broadcasting, operated at low power and restricted coverage, granted to non-profitable community foundations and associations, located in the area where the service it to be provided. Community radio is not a bootlegging radio.

### - **Programming**

Music and information with a stress on health information, on the radios aimed at the issue. In this radios shall be aired health campaigns, preventive medicine tips, public utility issues, ads from residents associations and assemblies, complaints about community problems and news programs with debates and interviews. The community radio would therefore work according to the needs of the community and availability of staff.

### - **Operation rules**

In the radios created with health as a priority, it is necessary that a Community Radio Project Managing Council be created, with parity formation

of community members and public health department (secretariat, foundation, health unity) and non-governmental organizations, if there is any involved in the project. The rules shall be published in the Official Daily Government Newspaper.

### - **Funds**

The public health department will be responsible for buying and installing the equipment and training staff. The community will be responsible for the operation and maintenance of the radio, that is, organizing the program schedule, besides receiving and airing ads.

### - **Basic equipment for operation**

Full loud speakers, wire rolls, professional record player, editing station, compact disc player, double caste player, microphones, amplifiers, equalizers, earphones, CDs LPs, and cassette tapes,

### - **Studio Assembly**

The place where the studio will be located, preferably the health unit, shall be plated with acoustic material (foam) and contain basic furniture.

Text based on Niterói Community Radio Project (RJ)