

World Fellowship for Schizophrenia and Allied Disorders

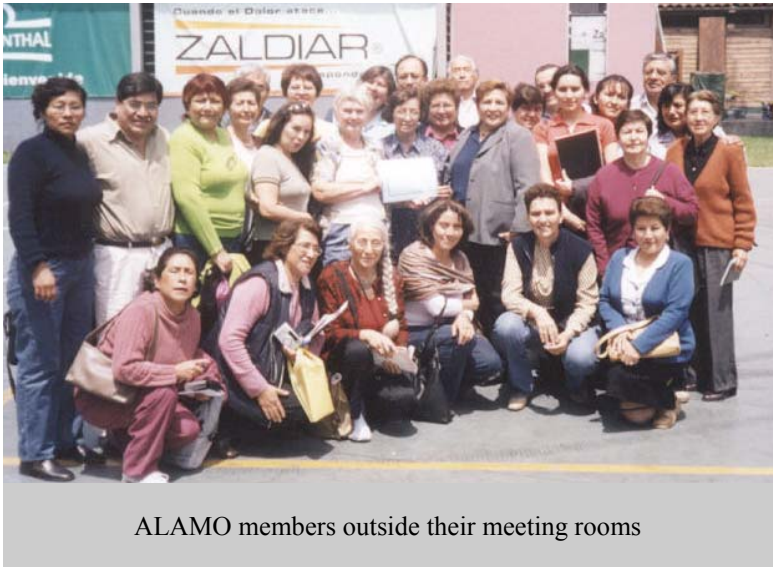
First Quarter 2006

**Strengthening Families through Empowerment
WFSAD visits Peru, El Salvador and Costa Rica**

Lima, Peru

Peru is a country of almost 28 million people. Lima has a population of 7.5 million. Just over half the country lives in poverty. This is particularly evident in rural areas. The possibility of exclusion and social anonymity are significant for the mentally ill. There is a very high rate of unemployment. Few state-run general hospitals exist, particularly in rural areas. There is no social security or disability pension for persons with mental illness. All health expenses are “out of pocket” (paid by the patient). Less than 20% of the population is covered by private insurance. Psychiatric care is given in the public (state) hospitals and in private clinics and hospitals.

Two years ago Mental Disability Rights International, a New York-based international charity, reviewed care in two psychiatric hospitals in Lima and found substandard facilities and treatment. Their report was not affirmed by the Peruvian govern-



ALAMO members outside their meeting rooms

ment. Although WFSAD had only brief visits to psychiatric hospitals, many of those we met confirmed the poor conditions in state psychiatric hospitals.

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The Goals of Strengthening Families Through Empowerment

The goals of the WFSAD Strengthening Families Through Empowerment program are many and varied. First and foremost, they reflect the needs of the organizations visited. To this end our work always begins much in advance of our visit with many exchanges between the proposed participants.

The program aims to promote the independence of family organizations, to develop their ability to advocate for their own needs and the needs of their community, and to expand their influence into the important issues of best practice psychiatric and psychosocial care and rehabilitation. In achieving these goals, family organizations are often faced with issues of human rights, stigma and discrimination.

Peripheral goals specific to the “Alianza Latina de WFSAD” are concerned with the development of this regional group through maintaining strong linkages between the member family self-help and advocacy organizations. There are opportunities for mutual advantage and collective action in relation to international governments—UN and its health bodies Pan American Health Organization; World Health Organization; World Psychiatric Association.

A three-week mutual exchange visit to three countries in Central/South America was conducted by WFSAD’s President Elect, Martha Piatigorsky and Secretary Diane Froggatt to motivate and strengthen family associations.

Following their stay in Peru, they were joined by Elena Chavez, Director of Alamo, Lima, Peru. Elena’s particular interests are human rights and disability. All three women traveled to San Salvador and San José.

This issue of the newsletter provides the highlights of each visit as prepared by Diane Froggatt and Martha Piatigorsky.

Lima, Peru (continued)

ALAMO

Our visit to Peru was hosted by ALAMO, a family and patient organization dedicated to rehabilitation and reinsertion into society for their consumers and education for their families. The group, led by Elena Chavez, consists of families, their relatives who are unwell and a group of voluntary psychologists who provide activities and help to those who are unwell. ALAMO has no specific premises of its own, but is loaned the facilities of a pharmaceutical company to conduct its twice-a-week sessions. ALAMO is concerned about the lack of availability of affordable medications and is making efforts to fight the taxes now imposed on psychiatric medications, which create additional barriers to treatment. ALAMO would like to grow, but without appropriate funding they cannot provide for additional patients and families despite support from a number of community volunteer professionals.

For the international visit, ALAMO had organized a meeting to promote mental health and showcase ALAMO’s and WFSAD’s activities to the wider medical and political community. Highlights of the workshop were presentations by Dr. Tulio Quevedo Linares, Director of Health Promotion in the Peruvian Ministry of Health and Dr. Edith Baca of the Pan American Health Organization. ALAMO social worker Elizabeth Aliaga gave an impassioned talk about working with patients and families. WFSAD representative Diane Froggatt spoke of the need to commit more health service dollars for the treatment and care of people with serious mental illness, and of the need to educate families so that they can cope with the 24-hour-a day, seven-days-a-week job of caring for someone with mental illness. She spoke of the global nature of WFSAD’s work and of the many groups like ALAMO that make up its membership both in Latin America under the banner ‘Alianza Latina de WFSAD’ and in many other parts of the world.

Martha Piatigorsky, WFSAD President Elect, joined Diane the following day to give an informal educational workshop to ALAMO members. ALAMO consumer members gave a humorous mime presentation on the subject of sharing which was great fun. The entertainers and their families then served lunch and we chatted informally about the program and the enthusiasm of the consumers.



Martha Piatigorsky leads ALAMO at WFSAD workshop.

Disability

During our stay in Lima we met briefly with congressman Javier Diez Canseco, president of the Commission on Disability of the Congress of the Republic. ALAMO is urging the inclusion of those with serious mental illness in those considered disabled. We also met with Acnes L. Mendoza Alvarado, vice-president of ASFEM, the National Association of Families of the Mentally Ill, located in Magdalena del Mar. WFSAD had been unaware of this organization. We agreed to communicate by e-mail.



Support meeting in Lima
Elena Chavez at centre

Thanks to ALAMO

We were made very welcome by our hosts at ALAMO, who enabled us to meet and speak to more than 200 people during our stay. Elena Chavez (abuelena@yahoo.com) works unceasingly to improve conditions for patients. The families of ALAMO are among the few receiving high quality care for their relatives through their psychiatrists and the psychologists and work activities given by ALAMO. We thank ALAMO for their hospitality.

Visit to Larco Herrera Psychiatric Hospital

In contrast to our visit to Valdezan Hospital, there was no warm welcome at Larco Herrera Psychiatric Hospital (photo of gates from inside, below). This hospital houses long-term patients, some of whom have been in the hospital 20 or 30 years. Rumours have it that this hospital may be closed down and is not accepting any more long-stay patients. We were shown round by the Communications Officer who was new to the hospital. We were not introduced to any families. This building was in a great state of disrepair. Rehabilitation is of the crudest sort and the facilities are substandard.



Gates of Victor Larco Herrers Psychiatric Hospital in Lima



Lima, Peru (Continued)

National Museum of Psychiatry takes shape in Larco Herrera Psychiatric Hospital, Lima

Victor Larco Herrera Hospital is a large old-style psychiatric hospital which is being downsized. A pavilion that used to be for children and adolescents (a service that has been closed down) now houses artifacts from hospitals that have closed.

By coincidence we met with anthropologist Diana Bustamante who is working on collecting, cataloguing and preserving artifacts from all over Peru that are concerned with psychiatric treatment in past days.

Diana opened the old padlocked doors of the pavilion and took us through the unlit, dusty hallway to her office and a set of rooms where the paintings, medicine bottles, photographs and all kinds of memorabilia are being looked after until either the building is renovated or new premises are located for a national museum of psychiatry.

We were able to see ledgers from former psychiatric institutions from as far back as 1899. These ledgers tell the history of treatment and care and Diana is painstakingly going through them and indexing them for interesting passages.

“There is not too much money for this work,” she told us. With a very small allocation of funds she is working enthusiastically to develop the museum. (dbm.59@hotmail.com)



Diana Bustamante, Museum archivist, with WFSAD president elect Martha Piatigorsky



Medicine bottles from a former era

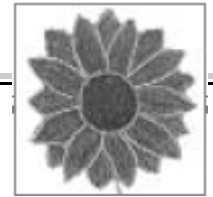
Valdezán Hospital Family Group



Staff and families with Dr. Bravo Alva at centre left wearing tie

We arrived at the psychiatric hospital “Hermilio Valdizán” to a warm welcome from Director Dr. Francisco Bravo Alva and his staff. A large group of families, patients and staff were very receptive to the WFSAD presentation “Strategies for Survival”. We left pamphlets and other information with Carolina Quespe Cardenas, president of the family group email: <fenix7779@hotmail.com>.

We were pleased to meet privately with Dr. Bravo and his director of administration and to tour the hospital, a vast acreage of pavilions looking rather run down. Nevertheless the hospital staff was positive and enthusiastic.



San Salvador, El Salvador

El Salvador is an essentially rural central American country with a population of six and a half million people. It has one major urban centre: San Salvador, with just over two million people.

It is now 14 years since the civil war, but the results of this are still evident in residual trauma, poverty and unemployment. A distinct dichotomy between rich and poor is evident from the large new shopping malls and multinational corporations to the small rural markets and pueblos. The currency is the US dollar. Health costs are “out of pocket expenses”. There are two public psychiatric hospitals in the greater San Salvador area: the State hospital and the Social Security Hospital. We were able to visit the latter. There are also private clinics.

ASFAE

ASFAE, our host in El Salvador, is the Asociación Salvadoreña de Familiares y Amigos de Personas que Padece Esquizofrenia y Otros Desorderes Mentales. (Salvadorean association for families and friends of those who suffer from schizophrenia and other mental disorders). ASFAE, led by psychologist Clara Isabel Iméry, is a family group for those with serious mental illness and their families. They meet regularly for education and self help and their executive is interested in advocating for better care. To educate families, ASFAE gives the NAMI (U.S.) “Family to Family” course twice a year. They report that though those taking the education were very pleased with it, ASFAE has yet to increase its membership by this means. We were interviewed twice on TV and once on radio by well-informed journalists.

Key Meetings

ASFAE Public Meeting—ASFAE organized a major meeting for public education and to encourage new membership. The program was diverse. Dr. Claudina Campos compared treatment and care in the different psychiatric hospitals. Seventy five percent of those seeking services for mental illness are treated in the Ministry public

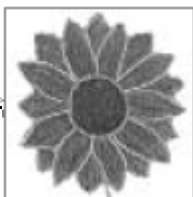
hospital, 15% by the Social Security Hospital and 10% privately. Mood disorders outranked schizophrenia by more than three times, although anxiety disorders were half as prevalent as mood disorders. Other slides described the way the system functions in El Salvador. (Slides available from WFSAD.)

Estimating a high percentage of families in the audience, Diane Froggatt gave a talk entitled “Strategies for Survival”, a WFSAD “coping” presentation; Yolanda Tablas gave a moving testimonial about her experience of the benefits of support and education offered by ASFAE; and Martha Piatigorsky defined what rehabilitation could be for people with mental illness and what people need to get their lives back. A number of new faces were seen at this meeting and ASFAE volunteers took time to speak with them individually.

ASFAE Private Meeting with the Ministry of Health and Council for Mental Health—This was a day-long meeting organized by ASFAE, at which board members and WFSAD representatives met with delegates from the Ministry of Health; the Council for Mental Health established by the First Lady; representatives from the Pan American Health Organization; and a lawyer from the Attorney General’s office. The meeting took place in the offices of the Department of Social Security. The tone of the meeting was very optimistic, laying out the government’s desire to improve mental health treatment and services. Key participants were Dr. Otto Moisés Castro, President of the Salvadorean Psychiatric Association; Moisés Guardado Rodríguez, National Program Ministry of Health; Efrain E. Campos, Executive Director, National Council for Mental Health; Dr. Eugenia de Villalobos, National Council of Mental Health; Oscar H. Linares, Department of Social Security - Quality Control; Dr. Francisco Paniagua, Psychiatrist advisor to ASFAE; Lic. Luis Enrique Salazar Flores, Attorney General’s office and World Health/ Pan American Health Organization delegates Amalia Ayala and Maritza Romero Porpiondo.



Photos: Above from left, Clara, Diane, Martha, Elena, Amalia & Maritza.. Centre: Dr. Eugenia De Villalobos, Efrain A. Campos & Moises Guardado Rodriguez. Right: ASFAE members Yolanda and Carlos



WFSAD Latin Alliance

El Salvador (Continued)

(Continued from page 5)

Clara introduced ASFAE as an active NGO working for the benefit of people with mental illness and their families. It is concerned with information, education, public awareness and discrimination and is working in all these areas to improve life for the mentally ill. The Ministry talks focused on health promotion and the necessity to have an active and involved electorate from all parts of society working with health professionals to improve general health determinants. The government needs to actively promote societal inclusion in improving the health of the population. The National Council for Mental Health is composed of representatives from all relevant ministries and other levels of government. There is no specific representative for those suffering mental illness. Activities are focused on the general mental health of the population with attention to those suffering mental health problems through disasters (earthquake, volcanic eruptions).

A Ministry presentation gave an overview of the planned program of care for patients and their families. We were pleased to hear the supportive position on raising the profile of mental illness offered by Maritza Romero and Amalia Ayala (OMS? PAHO). Human rights suggestions for an anti-stigma campaign were addressed by WFSAD, as these were likely areas of health promotion for the Mental Health Council of the Ministry. ASFAE members responded to the main presentations with questions and comments.

El Salvador 104th in Index of Human Development—

According to statistics given by Dr. Paniagua, El Salvador takes 104th place in the Index of Human Development. The country still faces the illnesses of underdeveloped countries. Health expenses are out of pocket for a most of the population, under a fifth have Social Security and a large percentage of the population live in poverty, with inadequate public services (\$48 per person spent per annum on health). We have learned that further meetings have now taken place between ASFAE and Dr. Villa Lobos.

Visit to Psychiatric Hospital (Ministry of Health)—This hospital is almost an hour from San Salvador on a major highway. There are few psychiatrists to look after 75% of the psychiatric population from San Salvador. The other 25% who have paid into the social security system are looked after in the Social Security Psychiatric Hospital (ISSS). Ing. Gloria Mena de Argueta, Product Representative at Eli Lilly, accompanied us and introduced us to Dr. Carlos Acevedo, Chief of Residency Education for psychiatrists in the hospital. We were able to meet with him later for discussions. From the beginning of their training, the residents have contact with the families of the hospital's patients who receive psychoeducation. We met Dr. Sandra Yamira de Garcia, Chief of the Women's Pavilion, who invited us to see the inpatient workshops. We met the Chief of Occupational Therapy, who was very interested in our work and our materials since it is very difficult to transfer the families from the hospital to San Salvador in order to have family meetings with ASFAE. We suggested the possibility of ASFAE arranging to visit the hospital on a regular basis. They will try to organize this. An interesting initiative in the hospital is the education of older adults as community leaders, preparing them to help families of mentally ill patients.

Visit to ACISAM

Another support organization in San Salvador is ACISAM. This organization works with the rural poor and those ill as a result of war. Recently they have begun to work with families and patients of the mentally ill providing education and occupational activities. They were interested in our ideas about "clubhouse" (a global model of care and activity focusing on the abilities of the mentally ill). We spoke to MSC Raul Antonio Durán Calderón, the executive director of ACISAM and to a senior psychologist.

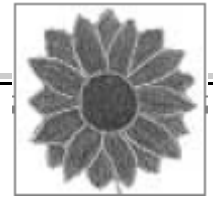
Thank you to ASFAE

ASFAE members made us very welcome, and were well prepared and well informed. The symposium with government officials provided a great deal of basic information that will be useful to ASFAE in their advocacy efforts.



Left:
Diane, Clara, Martha and
Elena at TV Studios prior to
their interview

Right:
Front row: Clara, Diane and
Martha
Back row: ASFAE members



San José, Costa Rica

Costa Rica is a country of four million people that has been free of war and civil conflict since World War II. At that time the country disbanded its army and introduced social security for its population. The national healthcare system is known as the Caja Costarricense de Seguro Social (CCSS). While the CCSS tries to provide a good health system, it is constrained by the limits of the Costa Rican and global economies. One fifth of the population lives in poverty. Medications for psychiatric conditions are available to the population, but second-generation antipsychotics are not regularly given because of their expense.

FUCÓPEZ

FUCÓPEZ is a Costa Rican family organization based in San José (a city of one and a half million) that reaches out to other areas of the country to deliver self-help and support to patients and families. The organization is politically active, striving for better care, rehabilitation and a future for persons with mental illness.

FUCÓPEZ had concerns about legislation, disability and stigma. At a working breakfast we had internal discussions about article 13 of a proposed law that says “in no more than 10 years after the passing of this law, the National Psychiatric Hospital (ed. the only one in Costa Rica) must reduce its population of inpatients to around 50% in relation to the national statistics. At the same time small inpatient units will be created in regional hospitals and other hospitals that can receive a proportional number for care, treatment with quality medications, and rehabilitation for social reinsertion.”

The fear is that by legislating the reduction of inpatients in the psychiatric hospital in 10 years this will indeed be enacted, while the second half of the law may not be fulfilled. It was thought that a separate article detailing the institution of care in general hospitals in 10 years might ensure community care. It was also thought

that it was important that the implementation of community care be entrusted to the new mental health policy and platform of the government as well as being made into law.

Visit to Psychiatric Hospital

We visited the National Psychiatric Hospital in San José. It is the only psychiatric hospital in Costa Rica and is built on a large acreage with many pavilions. There are 798 beds, around 400 of them for chronic cases in the hospital. People come from all over the country. Up-to-date methods of care are used, but there are few community services for patients after discharge. We met with nursing staff, María Isabel Vásquez and Douglas Mora. As far as possible they involve families, but many came from far away and it is not always possible to give them meaningful support and education.

Key Meeting

FUCÓPEZ had organized a day-long meeting involving mental health professionals, psychiatrists, politicians, families, industry and press (about 70 people). There were major speeches by Ministry of Health, representatives of WFSAD, and members of FUCÓPEZ. These talks addressed the upcoming legislation (see above) as well as stigma and human rights. A nice touch was a piano recital by a FUCÓPEZ member. In the afternoon, breakout groups worked hard on priorities for mental illness and managed to draw together significant issues that FUCÓPEZ could pursue in the coming months. These included working to improve the proposed legislation, organizing a public awareness campaign to sensitize society to mental illness, and improving the quality and price of medication purchased by government. (See www.fucopez.org for more information about FUCÓPEZ.) Certificates of participation in the course were presented at the end of the meeting.



Group returning from Lion’s Point beach



Master of Ceremonies
Juana Gaván



Martiza Meza with Ministry & WFSAD
officials



WFSAD Latin Alliance

Costa Rica (continued)



Barbaara, Rosalba and Raul from Nicaragua with Martha



WFSAD & FUCÓPEZ visit to National Psychiatric Hospital

Delegates from Nicaragua

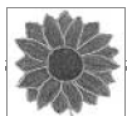
We were delighted that three family members from Nicaragua traveled many hours by bus to attend this meeting. They were given a warm welcome and took back much information to help them support their own relatives and to help begin a family self-help group.

Costa Rica involved in Research

We attended the regular monthly meeting of FUCÓPEZ at which Dr. Andrea Mesén, spoke of the development of Costa Rica's research agenda. Costa Rican researchers are involved in various American projects, particularly those involving genetics. Some of Costa Rica's inhabitants provide a rich genetic pool for research.

Fantastic Party

A party was held in the grounds of the Evangelical Church of which one of the FUCÓPEZ directors – Ester Rochas – was the pastor. There was a disc jockey and a Karaoke screen, along with refreshments of fruit juices and dinner. The evening was full of dancing and merriment and it was particularly noticeable how the patients/consumers enjoyed themselves dancing with each other and other guests and family. There was a high degree of companionship and love between them that was wonderful to see.



Collecting Stories to Improve Access to Treatment in Ontario, Canada

The Schizophrenia Society of Ontario (SSO), Canada, hears stories from many frustrated families in Ontario who attempt time and again, with little success, to get adequate psychiatric treatment and care for an ill family member.

Some of the many scenarios in which people with severe mental illness do not receive adequate and timely treatment include cases where a person:

- Meets the criteria for civil commitment or involuntary treatment and would clearly benefit from inpatient care, but is not admitted.
- Voluntarily seeks treatment in a hospital, but is denied admission.
- Is prematurely discharged from a psychiatric unit due to lack of hospital beds, even though the person may still be symptomatic and clearly in need of hospitalization.
- Is released without any hospital

discharge planning, consultation with family or plans for essential follow-up services and supports by hospital or community services.

SSO is documenting some of the problems, barriers and situations currently experienced by people trying to get treatment for themselves or a family member for use in advocating for improved access to treatment.

(Article excerpt from The Advocate, December 2005 issue of SSO newsletter.)



Tribute to a Brother: Jay Lawrence Johnson, 1953—2005

The many friends and colleagues of Dale Johnson – WFSAD's President – were shocked and saddened recently by the untimely death of Dale's eldest son, Jay Lawrence Johnson. The following account of Jay's life was written by his sister, Heidi Anna Johnson, Ph.D.

Jay Lawrence Johnson was born on March 2, 1953, in Lawrence, Kansas, to Dale Ladsworth and Carmen Jean Acosta Johnson. Sometime during his second year, the young family went to central Mexico to study the Mazahua culture. To this day, the Mazahua elders remember the red-headed baby with the deep-dimpled smile.

Sister Heidi was born in 1956, Father Dale graduated with a Ph.D. in Psychology, and the family moved to Houston, Texas. Brother Paul was born there in 1957. Jay was delighted to have younger siblings. He treated us as the favored subjects of a benevolent king, leading us into adventures that pushed precisely at the limits of our capabilities. Big brothers make the best babysitters, their motto being "If I bring them back alive, I've done my job." It's a policy that fosters bold and new experiences, even if a few knees are skinned along the way. Jay was the acknowledged leader of the block in suburban Bellaire, where he marshaled our kids in the Christmas tree wars against the kids in the next block. He would send scouting parties out to climb the back yard fences and bring back more trees. Our fort was impregnable. Designed by Jay, the softer firs lined the interior for comfort and the sharp-needed spruces ringed the exterior for defense. Jay and Dad built a scary maze for the Halloween festival at our elementary school – far and away the most popular event at the fair.

Jay had a happy childhood, as did we all: camping across the Western states, tagging along while our parents did research in Mexico, Guatemala, New Mexico, Washington State, and North Dakota, where we would stay with our indulgent grandparents. We went to Expo 67 in Montreal, and saw buffaloes in Mount Rushmore National Park. We visited museums and monuments wherever we went. I have a clear memory of sitting in the Remington Gallery at the Museum of Fine Arts in Houston, Jay and I on either side of Mom with Paul in her lap, while Mom told us stories about the scenes in the paintings. They were pretty grisly stories, as I recall. We loved them.

Jay was an Eagle Scout. He played the French horn. He lettered in swimming at Lanier Junior High School. He was Vice-President of the senior class at Lamar Senior High School. He painted in oils and made sculptures in clay. He loved science fiction and philosophy, pranks and puzzles, drama and debate. Our friends were always interested in what Jay was doing, what Jay thought – he was always in the vanguard of whatever caught his wide-ranging attention. He loved to sweep other people up with his enthusiasm and persuasive speech. He rallied a thousand students at his high school to march against the war in Vietnam. With his red hair and green eyes, expansive gestures and rich voice, his warmth and charisma, he was a compelling personality even as a boy.

Things must have started to change for Jay in his senior year of high school, though what may have been early signs of schizophrenia were camouflaged by the fluorescence of popular culture near the end of the war in Vietnam. He smoked pot and took acid – so did everyone, except the nerdiest nerds. There was a whole literature extolling the virtues of alternate realities that would have intrigued Jay even if he had not been developing schizophrenia. He cut a hole in his wall, to hide his stash, he told us. There were revolutionary books on just that very topic in wide circulation in anti-war circles. He cut a hole in the wall in Paul's closet to give secret access to the crawlspace under the exterior stairs. That was scarier, especially for Paul, but who were we to argue with Jay? He was going to Harvard, after all. Being forgivably self-absorbed in my own high school years, I don't remember much about Jay's first two years at Harvard. I do remember the day when Mom and Dad came to get us out of school, because Jay had just been sent home by the San Francisco police. The Jay we knew was gone; the poor boy we got back was wracked with terrifying delusions: John F. Kennedy crawling down his spine to kill him. He called me St. Anne and Paul St. Paul, and worried about having bear's feet. It was 1973.

There was little anyone could do for Jay for the next 20 years. He would run away, be missing for months on end, and then be found by some kindly law officer and sent home again. Eventually he was committed to the Texas State Mental Hospital, which could do little more than drug him into a



PERSONAL STORY (Continued)

Tribute to a Brother

(Continued from page 9)

stupor. Then in the '90s clozapine was developed and Jay was able to begin to have something like a life again. Although it damaged his physical health, the clozapine made it possible for Jay to live in a quarter-way house – a residential care facility in San Diego -- and to spend a few months each year in Taos with my parents. To me it seemed that the drug took the terror out of his delusions, so that he was able to stay in one place and be with people. He could hang out with the family at Christmas, go to the Ghost Ranch in New Mexico with the Taos Archaeological Society, and take art classes in the summer. He couldn't pay attention to anything for more than a couple of minutes, but he could be there, be with people, and that was a huge improvement over his previous condition.

Jay had 20 years or so of that relatively stable and comfortable life. My parents managed to provide him with as much pleasure, as much activity, and as much of a creative life as he could possibly enjoy during that period. But then he was stricken by another bolt from the blue, in the form of appendicitis. The complications that ensued were too much for his poor physical condition, and he died in the hospital in San Diego on October 8, 2005. He was 52 years old.

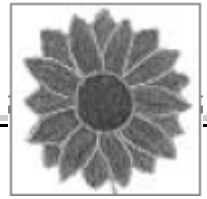
That's the true story. Things were better for Jay in his last years than we could have hoped for in the earlier decades of his illness, but still, that story isn't good enough for my brilliant brother. Jay loved science fiction, so I am going to give him an alternate history: a story of how his life might have been without the schizophrenia.

Jay would almost certainly have majored in mathematics at Harvard. He had the gift, and no professor worth his salt would have let that go undeveloped. He would have graduated in 1975, shortly after Bill Gates dropped out of Harvard to found Microsoft. Those were exciting times for the mathematically-inclined. Given two parents with Ph.D.s and the belief that math is a game best played by the young, Jay would have gone right on to graduate school. I think he would have gone to California – Stanford or Berkeley – drawn by the wildfire of creative energy in the computer

field. Xerox Parc invented the graphical user interface in 1973; UNIX was re-written at Berkeley around that time, launching the Open Software Revolution. Jay would have been in the thick of all that, fruitfully exploiting his gifts somewhere in the nexus of art and mathematics. He would have invented some deceptively simple thing that we all use every day, like the clickable icon or a file compression algorithm. It would have made him rich, as a side effect, but money and fame would never have been what motivated him. He would have liked earning money as proof of his cleverness, and loved giving money away, but holding on to it would not have held his interest. Jay loved ingenious things, tricky useful things, and he would have reveled in the passionate optimistic anarchy of the early days of software development. He would have been a vocal and persuasive advocate of open systems and free tools for everyone.

He would have married – more than once, I suspect. He would have had a few kids, and drifted into teaching as he grew into middle age. I can see his house as clearly as if it had really existed: a rambling Arts and Crafts beauty with wraparound porches, high on a cliff overlooking the Pacific. The exterior would have been landscaped by Paul K. Johnson. The interior would be crowded with artifacts from around the world and art created by Jay and his friends and his children. There would always have been lots of people gathered around his dinner table: siblings, friends, students, all coming by to ask, "Hey, Jay, what do you think about this?" He would examine the thing or thought in question and reply, in his rich, rumbly baritone, "All right!" He would have encouraged all of us to push the limits of our capabilities, to stretch our creative wings and soar as high and wide as we dared.

That's where I see him now, in my imaginary memory: holding court at his table, surrounded by family and friends and the colorful clutter of a full, creative life, arguing with cheerful ardor about truth and beauty. Jay Lawrence Johnson, rest in peace.



Drug Effectiveness, Adherence and the CATIE Study

Many of you will have read the *New York Times* article reproduced in our last issue (4th quarter p.10) that briefly reported results of the CATIE study conducted by Prof. Jeffrey Lieberman and his colleagues in the United States. Entitled "Effectiveness of Antipsychotic Drugs in Patients with Chronic Schizophrenia", it was reported in *The New England Journal of Medicine*, September 22, 2005 (Vol.353 No.12). We have now had time to examine the report and make some observations below.

Press reports in addition to the article in *The New York Times* generally concluded from the large study (1493 randomized patients) that second generation medications had no better efficacy than first generation compounds. However, these reports did not take into account the complexity of the study, the fact that it is only one part of a much larger study, the nature of human responses to taking medications and the fact that while some patients respond to one drug they may not respond to another. There are so many variables when studying patients' response to treatment that it is difficult to see how the press came to the conclusions they arrived at. Dr. Lieberman recognizes the complexity of treatment and the value of clinical judgment when prescribing medications. No doubt the study has given clinicians valuable information on which to base further such trials or methods of treatment.

Patients in the study had had schizophrenia for an average of 14 years. One quarter had alcohol abuse or dependence and 29% had drug abuse or dependence. With this in mind it was not surprising that a high number of patients dropped out of the study of their own accord. Family organizations, knowing the course of illness and the inadequacies of even the best medications, as well as the unpredictability of schizophrenia, can speculate as to the reason for dropping out of the study. An indication is the title of Javier Amador's book: "I am not Sick; I don't Need Help" which fully discusses the lack of insight exhibited by patients. Amador calls this "anosognosia".

During the study clinicians had the ability to increase or decrease the dose of the blinded medication as they thought fit. Unfortunately, the mere fact of blinding is likely to limit the physician's clinical judgment. In the real world doctors who are able to prescribe the newer medications to patients are

indeed prescribing and monitoring them carefully with good results. The press reports fly in the face of a huge basis of anecdotal evidence amassed by physicians and families.

One element that was sadly missing from this first report of the study was an investigation of the efficacy of clozapine, a drug which does not exactly fit into the category "second generation" but which has proved to be one of the most successful compounds for people with long-term illness for many years. Clozapine was used in phase 2 and will be reported in a future paper.

It would be interesting to see how patients with less chronicity are responding to current treatments. A very small study just published* of forty-four patients taking risperidone and quetiapine, whose duration of illness was from 2-12 years showed the efficacy of both medications over a 12-week period. One of the more notable facts, however, was that there was an average dropout rate of 43% even in this short period. The authors* do not touch on this in their discussion. In the next phase of the CATIE study perhaps the crucial issue of non-adherence will be examined.

Given the variability of symptoms and the lack of homogeneity in patients with schizophrenia, as well as limited knowledge about the possible causes of this syndrome, we commend Prof. Lieberman and his colleagues for attempting to determine treatment efficacy and eliminating the possible bias that can occur with industry studies. We look forward to seeing further results of the ongoing study.

Let us hope that policy makers and health insurers will see the necessity of using a number of different compounds in the treatment of schizophrenia rather than drawing erroneous conclusions from the first part of the study.

*Michael Reiden; Norbert Müller et.al. *Quetiapine has equivalent efficacy and superior tolerability to risperidone in the treatment of schizophrenia with predominantly negative symptoms*. Eur. Arch. Psychiatry Clin. Neuroscience. Published online 4 November 2005.



Asian Report — Reflections on 2005 Visits

By Jim Crowe, Chairman, Asian Region

Once again in 2005, I was able to travel to several Asian countries at no cost to WFSAD. The following provides the highlights of each visit.

Thailand

I traveled to Thailand for the Asian Advocacy meeting, which was held in Chiang Mai. Deputy Chief Monk of the Northern Thailand region opened the possibility of temples being used for community support and for families. Pairat Pruksachatkunakorn has done some very worthwhile work in his area in promoting family support work and in reducing stigma. It is his hope to be elected to the Thailand Senate in March 2006. Pairat presently sits as a judge in the youth court. We meet again next year. Let's hope it continues to be as fruitful as it has already been.

Singapore

This is a country which I have come to know so well. It's my cross road to all parts of Asia. There is now a very strong advocacy group working there called Action Group for Mental Illness. Recently the first family organisation was formed which is called Caregivers Association for Mental Health. Singapore continues to be very supportive in continuing the work both with the families and individuals. As it happens, I will be able to visit the families in Singapore early in 2006.

Malaysia

What tremendous progress has been made by families in this country. When I first visited here a few years ago, I found only a few scattered support groups mainly in or near Johore Bahru. Today there are over 40 family support groups around the country. Family Link – which has been written up by Marcus Chiu and others from Hong Kong – is used by a number of the groups. There is a fervent hope that sometime next year either the Malaysian Prime Minister or the Minister of Health will formally launch a National Family Organisation.

India

Earlier this year I was fortunate to be invited by Dr. P. D. Boaz to be a chief guest for the 40th Celebrations of the Dr. G. D. Boaz Memorial Hospital. What a great achievement.

Whilst there I was able to visit once again the Madras School of Social Work and share time with the students. My main focus as usual was families affected by a mental illness and its effects on

the whole family. The program Families as Partners in Care, I believe, still has tremendous merit. It was a valuable time as together we fully discussed the merits of involving families in their future work. The question time with the students showed their real interest in the area of family work and mental illness. I believe they will now begin to look more intensely at involving families in their work, and also, I hope, their training. I always feel that my visits to this school are very worthwhile. It is my hope that the seeds of future community work are being sown. Their next challenge will be community outreach.

I also visited the Madhura Narayanan Centre for Exceptional Children. It was a project of Dr. Boaz in his earlier days. Eventually he found that his work lay in the area of mental health. Perhaps visit http://www.mncindia.org/About_us.htm to learn more of the Centre. We have nothing like this in New Zealand.

While in India, I also responded to an invitation to speak to the students of the Department of Clinical Psychology Sri Ramachandra Medical College & Research Institute. The invitation came via Dr. Boaz from Dr. L. Sam S. Manickam, Ph.D., Professor in Clinical Psychology. I had the opportunity to speak to his students a few times. He is very keen on outreach into the community. I was also given the opportunity to speak to the full faculty. This included the department of Psychiatry and its students. It also has a teaching hospital, which I was invited to visit.

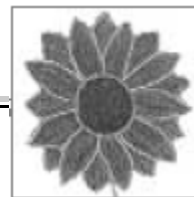
Another person I met who is held in very high esteem by the college was Dr. R. Gurumoorthy, Professor of Medicine, Chairman-Epidemiology and screening Committee. It was an honour to have him attend the faculty meeting.

My India trip also included a meeting with Dr. R. Nambi, President Indian Psychiatric Society.

It was my pleasure to be in Chennai when Aasha was about to open its second shop. Some of you may have visited Aasha whilst at conference. What a great job they are doing on behalf of the individuals and families. I have tremendous respect for what they have achieved over the last few years.

Finally, once more I returned to the Banyan along with my wife Ada. The Banyan is a tremendous source of inspiration by showing how much can be done with so little. Some 1300 women

(Continued on page 13)



The Banyan Client Group Speak Up for Rights

It is a decade since the historic People with Disabilities Act (PWD Act) was passed in India. To mark this occasion, the Banyan family decided to ask the client support group to speak for themselves on World Disability Day, December 3, 2005. (The Banyan is an organization in Chennai that cares for and rehabilitates homeless women with mental illness.)

The client support group comprises over 100 women who have been rescued from the streets and are either living independently in a group home and working outside, or living at the Banyan and taking part in the sheltered workshop.

The client support group decided that they wanted to voice their rights to the media so that a wider audience could understand the realities that they face and what they need from the government and society. Through their stories and opinions, they wanted to highlight issues that affect people with mental illness who have to face the trauma of the streets.

So the Banyan organized a press conference where the client support group addressed the media and submitted a draft of a petition that they prepared. The changes they wanted included giving mentally ill people the right to vote and recognition that mental illness is a disability. They asked why the mentally ill are deprived information on the benefits that they are entitled to according to the PWD Act of 1995. The press conference attracted the interest of local media, including articles of significant length in three newspapers.

The Banyan's current thrust is to continue fostering the client support group and empowering them to become increasingly independent. It's possible that the group will evolve into a movement that communicates to everybody, independent of any support from the Banyan or any other NGO.

Family delegate Appointed to Indian Mental Health Committee

The High Court of Karnataka, India, recently appointed Dr. Nirmala Srinivasan to the Committee on Mental Health Care as a representative of the consumer lobby. Appointment to this powerful committee gives Dr. Srinivasan an additional way to continue her advocacy on behalf of patients.



Dr. Nirmala Srinivasan

Some of the initiatives she is fighting for include:

- Ensuring there is a budget for mental health
- Making drug list more user friendly
- Addressing the shortage of psychiatrists

Dr. Srinivasan founded the group AMEND in Bangalore and then went on to establish an advocacy group called ACMI. She works constantly to urge the government to act with respect to mental health issues.

You can also find more about her work and views by reading the interview found at http://www.indianngos.com/issue/mentallydisable/interview_nirmalasrinivasan2.htm

Or go to:

<http://www.acmiindia.org>

Asian Report (continued from page 13)

have been rehabilitated all over India in the last 11 years.

The Banyan grows from strength to strength. What a magnificent approach to this highly demanding job. With more than 400 residents, they still see each resident as an individual. I met some of the women I had first met over 10 years ago, with some heavily affected by Hanson's disease (Leprosy). I firmly believe that had the Banyan not existed, the women I met in this house would not be alive today. This house was established for those whose families could

not be either traced or found. (For more information on the Banyan, see above for "Banyan Client Group Speaks Up for Rights".)

My next few journeys will focus not so much on papers but working out in the community. This is where I began. It's time to work more closely alongside families in their homes and clinicians.

Jim Crowe is Immediate Past President of WFSAD.



BApK — Family-Self-help Psychiatry of Germany celebrates 20th Anniversary

By Ursula Brand and Leonore Julius

With the motto "Living with mentally ill people – with confidence and solidarity" – BApK, the Family-Self-help Psychiatry in Germany celebrated its 20th anniversary in 2005. The Family-Self-help Psychiatry is the self-help organization and support group for relatives of people with mental illness and a lobby group that operates at all political levels in Germany.

Brief Historical Account

Self-help and support for those affected by mental illness and their families began with the first family support group in 1976, and in 1982 families of people with mental illness met in Bonn for the first national conference. These events marked the beginning of the family movement in Germany; the federal association – Bundesverband der Angehörigen psychisch Kranker (BapK) – was registered in Bonn as an independent charity or NGO. Today there are Regional Associations with many family support groups (about 500) in all federal states, including the new states in eastern Germany. Local groups constitute the backbone of the family movement in Germany; it has remained a pure self-help organization.

BApK's Mission

The struggle against discrimination and stigmatization of the affected persons and their families comes at the top of the list of BApK's goals. High priority is also given to the demand for the same rights as for those who are physically ill, for modern methods of treatment, the best possible rehabilitation, social security and the provision of care appropriate to the need of those who are ill and their families.

BApK are active partners in two Research Networks in Psychiatry: schizophrenia and depression. The objective is to study factors related to early diagnosis, prevention, acute and long-term therapy as well as rehabilitation and to incorporate results into clinical practice. BApK is also involved in developing new guidelines for the treatment of schizophrenia and depression.

BApK has also launched two national programs. One is a joint project with the Federal Association of Corporate Health Insurers. It addresses companies and organizations with the aim of preventing unemployment because of mental illness and providing assistance in dealing with affected employees before critical situations arise or escalate. The second project, called "Enlightenment – Information – Help", is a low-level education campaign targeted to practitioners; advice centres and the general public. For more information, write to: Familien-Selbsthilfe Psychiatrie, Main Office, Am Michaelshof 4b, 53177 Bonn, Germany.

Progress in Uganda

Thomas Walunguba, Chairman of the Uganda Schizophrenia Fellowship (USF), gave an update on USF's 2005 activities at a recent gathering of about 72 members and supporters of the organization.

Achievements included:

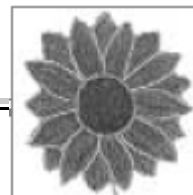
- To help achieve the objective of reducing anxiety, discrimination and stigma, a play entitled *Twogwanu Sumbi* (never lose hope) has been written by members, and another member has written a poem, both of which have been performed and recorded.
- Interacting with members of the hospital administration to educate and increase awareness
- Hosting a visit from John Cox, instructor of community social service workers of Douglas College in New Westminster, B.C., Canada
- Strengthening collaboration with WFSAD in Toronto, Canada, and Reason Partnership UK

Home visiting, supportive counseling and support meetings also continue, however home visiting is still difficult for most fellowship members due to lack of funds for transport. Lack of funds also meant that no further construction could take place on the new USF building at Jinja. You can write to Walunguba Thomas at P.O. Box 27321, Kampala, Uganda.

Focus on Anti-Stigma in Bangladesh

Badrul Mannan of the Society for Welfare of the Schizophrenic in Bangladesh reports that the organization has launched a program to apply stickers showing anti-stigma words to inter-district buses that travel nationwide. They were able to mark World Mental Health Day with the inauguration of the program on government buses. They plan to have 100,000 stickers in total. Badrul also took part in a television program on mental illness hosted by another NGO. They are also planning a web site which will hopefully help their fund raising efforts.

ACKNOWLEDGEMENTS



The board, the staff, the volunteers and the members of the World Fellowship for Schizophrenia and Allied Disorders give their sincere thanks to all those who have given support to us for 2006. In particular we would like to acknowledge the following corporate and foundation donors and grantees:

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In addition we thank those many individuals who are contributing to our mission to help “alleviate the suffering caused by schizophrenia and related disorders”.



This newsletter is an international bulletin published by the World Fellowship for Schizophrenia and Allied Disorders (WFSAD). Our goal is to provide information to the world self-help movement for schizophrenia and allied disorders that includes national local organizations, individuals coping with illness and friends and professionals.

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World Fellowship for
Schizophrenia
and Allied disorders
124 Merton Street, Suite 507
Toronto, Ontario M4S 2Z2
Canada
Phone: +1 416 961-2855
Fax: +1 416 961-1948
Email
info@world-schizophrenia.org
Website
www.world-schizophrenia.org



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WFSAD Conference

Lighting the Path:

Carrying the Torch for Mental illness

TRAINING DAY PRIOR TO CONFERENCE: 27TH SEPTEMBER—DETAILS LATER



The World Fellowship for Schizophrenia and Allied Disorders with its partners the Schizophrenia Society of Canada and the Schizophrenia Society of Ontario have obtained the services of Solby, Shockley and Grant to organize the 2007 world conference. The venue for the event has been chosen: the Delta Chelsea Inn in downtown Toronto. We are pleased to welcome to the conference team the Schizophrenia Society's new Executive Officer, Mary Jardine, who has served as the National Executive Director of the Parkinson Society of Canada. Mary has worked in both salaried

and volunteer positions across Canada for over 20 years. Other members of the team are John Gray, president of SSC and a member of the WFSAD board, Mary Alberti, the Schizophrenia Society's long-time Executive Director, as well as WFSAD President Dale L. Johnson and Members of the Board.

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