

INTERCOM

Special issue on Special Olympics and Agnews Hospital

THE COMPUTER HISTORY MUSEUM

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Memorex Volunteers Support Local Special Olympic Games

President John Kennedy once said that a nation's greatness can be measured by the way it treats its weakest citizens. Many nations are now helping to make their weakest citizens stronger through Special Olympics.

Since 1968, when Special Olympics was created by the Joseph P. Kennedy Foundation, more than two million retarded children and adults have experienced the joy of play and received the benefits of physical training and sports competition.

Special Olympics is a grass roots program whose durability and strength are shaped by the dedication and commitment of its small professional staff and its hundreds of thousands of volunteers in local communities throughout the United States and in more than 40 nations of the world.

Just a few years ago, it was different. Most mentally retarded individuals had no physical education at all. Many of the "experts" believed that the retarded couldn't leave their homes or institutions to travel. They said the retarded would get disoriented and upset if they were taken out of their protected environments. They said the retarded couldn't run as far as 300 yards or swim 25 yards or take part in team sports. They said the retarded wouldn't know the difference between victory and defeat and, in any case, they should not be exposed to competition.

But the first Special Olympics Games were held in the summer of 1968 and the rest is history. In the 15 years since that first track and field event, Special Olympics has become the largest sports program of its type in the world.

It has gone from a handful of track and field and two swimming events to a truly Olympian contest, involving such sports as diving, soccer, basketball, softball, track and field, swimming, volleyball, bowling, frisbee throwing, all kinds of hockey, gymnastics, skiing, ice skating, and wheelchair events — most of which the "experts" said the retarded could never learn to perform.

Special Olympics does not involve a giant bureaucracy, nor does it rely on legislative action or public funds. Its programs and support arise out of the dedication and efforts of volunteers who believe that the mentally retarded have a contribution to make to society if given the chance to learn, experience, and grow.

No retarded person is too handicapped to participate. No time is too slow, no distance too small to earn a ribbon, a hug, or words of encouragement. Special Olympics prizes equally the runner who crosses the finish line of the hundred meter dash in 11 seconds and the runner who finishes in 50 seconds. All participants are winners.

The Special Olympics oath, recited by the athletes before each contest, goes, "Let me win but, if I cannot win, let me be brave in the attempt." The mentally retarded need Special Olympics for healthy growth and self-confidence. Even the most handicapped individuals possess courage and abilities that deserve their public moments.

Yet, despite the amazing success of the program, there are still mentally retarded children and adults who are denied the chance to participate, to develop their physical abilities, and to experience Special Olympics, simply because of a lack of funds and volunteers.

Funding is a special problem in state-funded institutions, such as Agnews Hospital. Because of severe budgetary limitations, there are limited funds available to subsidize resident participation in Special Olympics, or summer camp, or other special events.

To meet that need, Community Volunteer Services to Agnews, Inc., sponsors the annual Community Awareness Faire for the enjoyment of people in the community and as a fund raising event for the extracurricular activities of Agnews residents. The Faire includes professional entertainment, games, food, arts and crafts, a parade, music, an auction, bingo, and other special activities.

Nationwide, major corporations such as Coca-Cola, Warner Communications, McDonald's, AMF, Kodak, Procter and Gamble, Levi Strauss, Norelco, and others have made significant contributions to support the success of Special Olympics. In Santa Clara County, Memorex is the only Corporation to date that has shown an interest in supporting the residents of Agnews Hospital in participating in Special Olympics.

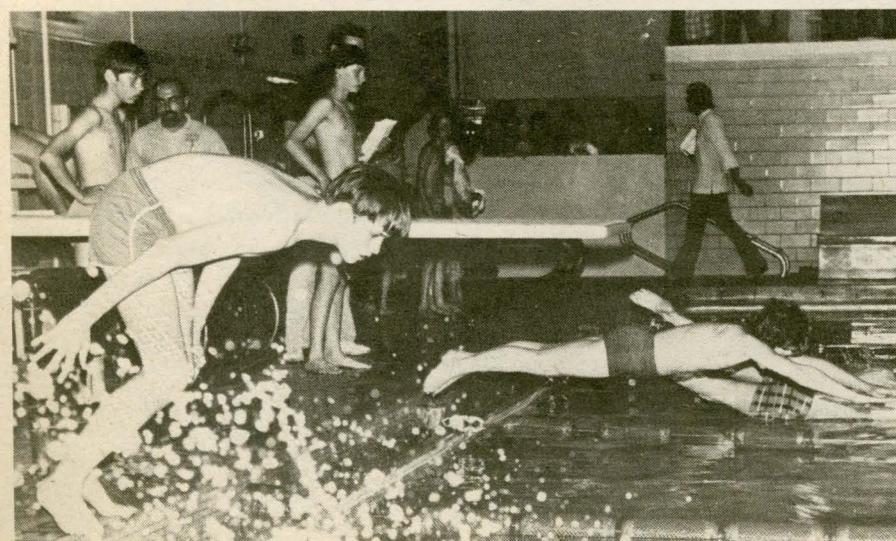
Last summer was the first year of our participation, in which we donated Special Olympics team t-shirts to Agnews Olympians and recruited employee volunteers to assist at the Games. The summer of 1983 marks our second year of participation, a year in which we will also be supporting the major fund raising event — the Community Awareness Faire.

Clancy Spangle, president of Memorex, has taped a public service announcement requesting that members of the community, including Memorex employees, attend and enjoy Community Awareness Day on Sunday, May 22. Some Memorex employees have already volunteered their talents and time to publicize the Faire. Other employees have volunteered to assist at the Faire and at the Special Olympics events being held this summer. Many more volunteers are needed.

Nationally, some of the most well-known Special Olympics volunteers are: Julius Erving, Gordie Howe, Pele, Hank Aaron, Jim Plunkett, Ron Guidry, Kathy Rigby, Dick Button, Donna DeVarona, Bruce Jenner, Wilma Rudolph, Wilt Chamberlin, Muhammed Ali, Don Meredith, Mark Spitz, Bobby Orr, Arnold Schwarzenegger, Rosie Grier, Arthur Ashe, JoJo Starbuck, Roone Arledge, Steve Garvey, Rick Barry, and many, many more.

When Ron Guidry of the New York Yankees received the Spirit of Special Olympics Metal — the program's highest award — he told of how in his mother's home in Louisiana, two framed awards hang side by side — equally prized, equally cherished by his mother. One is Ron Guidry's Cy Young Award. The other is the medal his brother Travis won in the Louisiana Special Olympics. "And, you know," he said, "I believe it took more character and sheer guts for Travis to win his medal than for me to win the Cy Young."

If you wish to volunteer, call Betty Thomas at 996-9000, extension 304. The Community Awareness Faire will be held at the West Campus of Agnews, corner of Lafayette and Montague in Santa Clara from 9:30 AM to 5:30 PM on May 22.



An Interview with Keri Procunier

Keri Procunier is the director of Agnews Hospital. She was recently interviewed for this special issue of INTERCOM.

INTERCOM: What is the history of Agnews Hospital?

PROCUNIER: Agnews was constructed in 1885 with the intention that it be a facility for the mentally ill. This leads to some confusion about our present role. Back then, it was called Agnews Insane Asylum, which was considered to be a very progressive name. The 1906 earthquake destroyed the original five-story clock tower building that spanned out over about 20 acres on the West Campus.

After the quake, some of the more difficult residents were sent to Stockton State Hospital. The other patients (in those days, they were called patients — now they're called residents) helped to rebuild the facility. After it was rebuilt, expansion began.

It was out in the country, as the philosophy of the time was to put the mentally ill people away so that others would not have to be exposed to them. People tended to hide any disabled or unusual person away from the community.

It may be very interesting to note that, if you read the old record books, you find that some of the reasons people were admitted to state hospitals, aside from a good percentage who really were mentally ill, were because they were indigent, divorced, or in some cases, women were committed by their wealthy husbands to get them out of the way because the laws weren't there to protect people.

Now, we've finally moved in the other direction to protect the patients and residents at both types of hospitals — for the mentally disabled (mentally ill) and the developmentally disabled (mentally retarded).

In the 1930's, the state purchased the piece of land that became known as the East Campus, which is in San Jose. At that time, it was orchards and the idea was to put patients to work taking care of the agricultural lands, running a hog ranch, and working toward Agnews becoming self-sufficient and self-contained. Also, during the 30's, crowding at Agnews started to occur. It was decided then to build just one building on the East Campus for the people who were tending the land. And, as one could predict, the East Campus also became crowded.

Construction continued on the East Campus until we had everything but a hospital unit.

From its inception through the expansion and into the early 70's, Agnews was still a facility for the mentally ill, so one can well imagine why people in the community remember Agnews serving only that population's needs. It had a very fine reputation nationwide as a facility for the mentally ill and was written up in many professional journals at the time. It was considered to be very progressive for the time it existed as that type of facility.

In the 1960's, a plan was developed by the State of California to de-institutionalize residents of state hospitals. The concept was to disburse the patients back into their home communities. For example, the plan was to move individuals from San Benito County back to San Benito County and place those people in outpatient clinics or some type of board-and-care facility, give them their therapy and medicine in a setting close to home and, in effect, create local mental health systems. Even though there was, and still is, much debate over the plan, it is a very sound concept if the money and programs are there to support it.

By the mid 1960's, Agnews had come up to almost 5,000 residents living on both campuses. If you look at our campuses now, and we think we're full at 1100 residents, one has to wonder how programs were maintained with 5000 residents and minimum staff. Staff who were here then were running units with 75 people on them. Today, we would never consider more than 30 people on a unit with much higher staffing ratio.

Out in the public, you generally hear a lot of criticism of state hospitals. I truly maintain that a state hospital is a reflection of society's ideas and philosophy of how to care for people who have special needs.

Around 1964, when Agnews began disbursing their mentally ill back into the community or into other facilities, we brought in the first group of developmentally disabled people, then referred to as "mentally retarded" individuals.

The original group of about 500 individuals were brought here to get the "finishing touches." They were already fairly independent but needed to work on job skills and daily living skills. Some of the residents were able to go out into the community to hold a day job, then return in the evening to our facility.

In 1972, after disbursing all mentally disabled from Agnews, we closed the doors to the mentally disabled and no longer accept those individuals.

In many respects, it is easy to see why people in the community are still confused. Even though there was a lot of publicity about Agnews closing its doors to the mentally ill, no one was simultaneously announcing, "but we are continuing service to a whole new population, the developmentally disabled or mentally retarded."

INTERCOM: Do you still have people call or come out here who feel they are mentally ill and need help?

PROCUNIER: Yes. We refer them to a county mental health agency or to Valley Medical Center's psychiatric unit. Some are former patients who don't know where else to go.

INTERCOM: What kinds of care do you offer the residents?

PROCUNIER: We offer a full range of care including medical and physical care, educational, rehabilitative (such as sheltered workshop care or work programs), and activity and leisure-time programs. Each resident is seen by a variety of professionals and paraprofessionals in the facility. So, as you can see, we have a full range of services.

The only thing we do not have is major surgery. We have a very good arrangement with Valley Medical Center whereby they immediately take those residents from our acute infirmary when we feel that surgery or very specific acute care is warranted. By arrangement, we bring them back here as soon as possible because we have the staff who know how to deal with our residents. We are very fortunate to have such a tremendously good relationship with Valley Medical Center.



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INTERCOM: What changes, if any, have occurred in the last 20 years in people's attitudes about the mentally retarded, and why?

PROCUNIER: In the 1940's, right after World War II, advocacy groups of parents began demanding that their developmentally disabled children had rights. During the 1950's, trainable mentally retarded were entering the public school systems in special programs. However, the developmentally disabled in the 1960's still had not received much acceptance. At that time, the idea of educating the developmentally disabled was just becoming acceptable. Much of the credit for today's different attitudes has to go to the active parents and to the Kennedy family. President Kennedy's family openly admitted that they had and deeply cared for a developmentally disabled sister. Because of that, there was generally more acceptance of the disabled. The advocacy of parents of developmentally disabled individuals also had a lot to do with the gains that have been made statewide and nationwide for this group.

INTERCOM: What are some of the changes that have taken place in treating and teaching developmentally disabled people in the last 20 years?

PROCUNIER: We keep learning more and more about our residents. Now, we really stress practical training. For example, there's no sense in someone spending three years learning how to add if that's not going to be practical or worthwhile for that person. Or spending seven years learning how to tie shoes if their coordination is so poor that it would be much simpler to learn to put on loafers. We can spend that energy on more practical things, such as not stepping off a curb when a car is coming or finding a bathroom or eating appropriately.

Very often, the residents at Agnews fall into three categories. We have the medically fragile who, in many respects, need total care. Sometimes they're here for a very short period of time because their lives are so fragile.

Then we have a large group that averages about age 35 who are severely retarded. They can usually feed themselves and care for themselves but have none of the refinements we think of, such as buttering their bread or eating family style. The staff will work very hard on these skills because, in time, the extra work it takes* for the staff to teach them will pay off when these people learn how to care for themselves. It also pays off for the taxpayers because less staff are required when these people can perform the basic skills we take for granted.

The third group or major type of resident is our behavior adjustment resident. The individual may be severely or moderately retarded, but his or her behavior is not acceptable in the community. We work very hard to alter or lessen the unacceptable behavior by using behavior modification techniques.

INTERCOM: Does the average person ever get used to being around severely retarded people and be comfortable around them?

PROCUNIER: It depends. I would say that, more often than not, they do. It is uncomfortable to be around anyone that is different. You're not sure how they're going to act. If you've never been exposed to the developmentally disabled, it's difficult enough on a one-to-one basis, but if you come out to an activity here, then you're looking at maybe 200 individuals who can be very different looking in some respects. If you return, the second or third time your difficulties are going to go away. They really are. And there's nothing wrong with that group of people who feel they just can't deal with our type of residents. Remember that there are other ways you can support special needs people.

Our residents are just people, but people with a lot of sensitivity, a lot of feeling. They're very sensitive to emotions and, like most of us, can sense how people feel about them.

You may wonder how to talk to them or if they understand you. The best thing is just to talk normally. They'll pick up what they want to pick up and what they can pick up. Don't be concerned when they talk to you and you can't understand them. You can say, "I don't understand what you're saying to me." Or, you can ask a staff member, "What is he trying to say to me? What is she trying to get across to me?" The residents appreciate that and there's no sense in patronizing them. They are human beings who deserve to be treated with some dignity. I don't think that's too much to ask.

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INTERCOM: What services, if any, are available for families of developmentally disabled people?

PROCUNIER: When a family has a developmentally disabled member, they get in touch with the San Andreas Regional Center. Even if they are not referred to Agnews, they will offer a lot of social services and back-up services to help the family. If they do come to Agnews, through the referral from the regional center, our staff and social workers will assist the parents, relating individually to the different parents. The family may develop a very close relationship with the social worker or the group leader that takes care of their child. Some of our families are really able to verbalize what they've gone through themselves. It's well worth it to hear some of the things they've had to deal with, like the guilt they face when their son is 18 years old and is acting out and maybe needs total care. They may think, "I can't do it any longer. I can't care for him and I'm going to have to place him somewhere."

Then, they go through misgivings and wonder, "How is he? Are they taking care of him as well as I do? Do they really care for him? Do they know that when he has the sniffles, he's almost on the verge of pneumonia or do they know he's pretending sniffles for the attention?" They consider these things as any parent would.

I think that whenever you have a parent walk into your office with their concerns, you have to place yourself where they are and ask, "How would I feel if that were my child?" Whether you have one child or eight children, they are very precious individuals to a parent and, if you're any kind of a parent, you are concerned enough and caring enough to want to know what other adults are doing with your children.

What I tell people in orientation is, "Don't ever try to judge other families." Every family of a special needs child has to make some difficult decisions and they have to decide what's good for the whole family, not only for the special needs child. I'm not even sure I know how I would deal with such difficult decisions. I don't know what decisions I would make and don't think anyone does until they're faced with the issue themselves.

INTERCOM: Do you have any extraordinary success stories of residents?

PROCUNIER: Yes. This one, for example is really unusual and I share it with you with the idea that it is the unexpected, the unusual. We don't want anyone thinking that someone who comes in here mentally retarded/developmentally disabled leaves "okay." But, we have had some really unusual situations. This is one.

About a year-and-a-half ago, we had a three-year-old boy come in who had been a drowning victim. Drowning victims, if brought back to life after being under water, are comatose. They are very, very rigid and have little response. There may be some response out of the eyes but not really to the persons around them. The experts are still not sure what they are retaining or whether they are even hearing sounds, so they must be totally cared for. They are fed through tubes and everything else is handled for them.

This child's family was Vietnamese and spoke very little English, but they would come daily to the chapel and pray together as a family. We could see that they were a very loving and caring family and cared greatly for their child. We gave them no encouragement. You just don't. There's just no way to be honest with a family and say, "We'll give it some time." You don't want to give up all hope but, on the other hand, it rarely occurs that a drowning victim will come out of that stage.

Within about six months, we started to see some response with him. We saw some eye response and some movement. A year after his placement here, he was discharged and had regained all facilities. He was verbal and comprehended normally. That is really an unusual case — the kind that cannot be explained.

INTERCOM: Do you ever need volunteers? If so, for what?

PROCUNIER: Yes. We need volunteers for every major activity we have, including Special Olympics and camping. Memorex employees over the last couple of years have become extremely involved in Special Olympics and that's been wonderful

Volunteers may feel a little uncomfortable around our residents at first, but if they come out with someone who's volunteered before and can tell them, "It's going to be okay," volunteering is much easier.

Because so many of our residents (about 300 or 400) are in wheelchairs and are non-ambulatory, we need a one-to-one relationship with a volunteer. We never pair volunteers up with a resident if the volunteer is going to be uncomfortable or maybe the resident demonstrates an "acting out" behavior. We pair volunteers up with people who we feel are pretty steady, residents who just need some tender care or need their wheelchair pushed or some kind of guidance. The staff takes care of anyone that may have to be watched a little more carefully, may have seizures, or may have some problems in some other area. These are not the individuals we place with volunteers.

We have over 1000 other residents who need one-to-one volunteers for various events. Aside from Special Olympics, we need volunteers for camping, in the summer and other good-weather months (I'm beginning to wonder when the good months are in Santa Clara County).

We have a camp adjacent to Coyote Creek that was brought into existence by the Community Volunteer Services Board, a non-profit agency that serves the hospital so outstandingly. The structure and the kinds of equipment that are used for camping are all out there. When we go camping, the more volunteers we can get — either for the one-day or the two-day trips — the better the camping experience. And it's a good activity for volunteers, particularly if it's the first time.

We can always use clerk-typists and people to do filing and other help of that nature. Also, we have people who have volunteered to handle the books for the Community Volunteer Services Board. They come out and religiously take care of the treasury account. We have a group of women, many of whom have children out here, who volunteer every Wednesday to make arts and crafts to be sold at the Community Awareness Faire and at boutiques to generate funds. They have a very worthwhile experience.

I think there are some people who may want to volunteer but they may be somewhat reluctant about being involved individually with a resident. There are lots of ways for people who have time to volunteer to assist in other nonresident-involved ways such as plant operations. We have all kinds of projects that go on the back burner because our staffing does not allow time for many of the extras.

"I have learned that every person out there will, in some way, be touched by knowing a little bit more about developmentally disabled individuals."

INTERCOM: Why is it important for people in the community to understand what Agnews is all about?

PROCUNIER: I think because we are part of the community. We are part of their neighborhood. We are a significant part of the Santa Clara Valley. I have learned that every person out there will, in some way, be touched by knowing a little bit more about developmentally disabled individuals. Hopefully, they will not have to face dealing with decisions about a special needs child themselves, but just as you think it won't happen to you, statistically it will happen to someone close to you. Maybe it will be a friend or a cousin or a sister. People need to know who we are and they need to know that there are a lot of other services out there for them.

Many times, members of the community don't even know where to turn for help with an older person that has a problem or they're dealing with the developmentally disabled person alone.

INTERCOM: Any closing remarks?

PROCUNIER: I'd like to share with Memorex employees our real appreciation for your involvement. We have not had a company at the level or size of Memorex assume the involvement you have. I know it's growing and it's greatly appreciated. The benefits are twofold: we get the volunteers and our nearly 1100 residents are able to participate more because you're involved. I know it's difficult to do that first time as a volunteer, and I would like to thank the Memorex employees who have taken on this challenge. Our residents truly appreciate you!

agnews awareness **FAIRE**

SUNDAY MAY 22
9:30 ~ 5:30

*antiques & collectibles silent auction
parade • food • wine tasting • plants • bingo
games • arts & crafts • special guests
music & entertainment
and more!*

AGNEWS STATE HOSPITAL
west area
lafayette & montague streets, santa clara

all proceeds to benefit residents of agnews