#### Memorandum

Date: August 12, 1993

To: Senator Dole

From: Alec Vachon N

Re: FYI/Attached Article on Jerry Lewis

The attached profile of Jerry Lewis appears in September's <u>Vanity Fair</u> -- takes him to task for his"pity" approach in the annual Labor Day Muscular Dystrophy Association (MDA) telethon (see, e.g., pp. 86-87, 92). The article also presents Lewis as an unpleasant, overbearing jerk.

Evan Kemp, former Chairman of EEOC, is a long-time critic of Lewis; discussed on pp. 92 and 94 (photo p. 84), together with personal problems Kemp and others have encountered in taking on Lewis and MDA.

On page 92, Stephen Mikita is mentioned -- a former MDA poster child and currently a State Assistant Attorney General in Utah. A strong Lewis supporter, Mikita stopped by to visit with me several weeks ago. Although a Republican, he is campaigning for an Administration job. (The meeting was set up by Jack Gannon, acting Chair of the National Council on Disability and former President of the International Firefighter's Union. A get-acquainted meeting; no assistance by this office was requested or offered.) Initially, Mikita wanted to be an EEOC Commissioner, but no "Republican" slots are expected for some time. After meeting with a senior White House senior personnel official, he now apparently expects to be offered Deputy Assistant Attorney General for Civil Rights or General Counsel at EEOC.

The article also suggests possible improprieties in MDA's operations.

> Above, Jerry Lewis with his "kids" at the annual M.D.A. Labor Day telethon. Left, at home in Las Vegas, the 67-year-old Lewis waits alone.

# JERRY VS. THE KIDS

His Labor Day telethons have raised millions for muscular dystrophy, but Jerry Lewis, King of Comedy, is under siege from disabled adults who say their "pity-mongering" patron has become patronizing. And Jerry's anger is no laughing matter

#### **BY LESLIE BENNETTS**

leave the restaurant, an aged hippie with long, lank hair holds out an ancient record album for Lewis to autograph. He takes it with a benevolent smile. From the album cover, his own face grins idiotically-up at him, 40-odd years younger: this was Jerry Lewis the monkey, as he used to describe himself, the comic who was willing to make a fool of himself in any way to get a laugh. The valetparking attendant looks at the album cover, checks out Lewis's face, and clutches her heart. "Oh my God!" she gasps. "Jerry Lewis! I can't believe it's you! Oh my God! Oh my God!" By now Lewis is looking positively cheerful. His car pulls up and we get in, even

ntil he tells me about the reporter who asked him where the money goes, Jerry Lewis and I seem to be doing fine. I already know he considers journalists to be ''stupid whores'' and ''morons,'' but he's being very nice. It's taken more than a year to

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persuade him to see me; his longtime hatred of the press has been exacerbated recently by coverage of the anti-Jerry Lewis protests being mounted around the country-by the disabled, of all people. Lewis has spent more than 40 years working on behalf of those with neuromuscular diseases, and now some are accusing him of demeaning them with the so-called pity approach which has long been a hallmark of the annual Muscular Dystrophy Association telethon. This makes him very mad. But here we are, in a nice little Italian restaurant in San Diego where all the waiters bow and scrape, and everything seems warm and friendly.

Then he starts talking about some reporter who was investigating charitable fund-raising-including that of the Muscular Dystrophy Association, which Lewis has been involved with since the early 1950s. "I told her, 'If you do anything to hurt my kids, I'll have you killed, you understand?' " he says, very deliberately. He raises an index finger and starts shaking it, slowly and meaningfully, right in my face. His face is getting red; his voice begins to rise. "I'll have you killed," he repeats. "I'll have you killed!" By this point he is almost shouting; I'm no longer sure whether he's recalling his anger at somebody else or yelling at me. I stare wide-eyed at his big onyx pinkie ring. J.L. is glaring at me; his eyes are dark with fury.

Finally he withdraws his finger from under my nose and resumes eating his pasta, looking resentful. O.K., J.L.: message taken. Since he has already told me some eye-opening, but off-the-record, stories about his lifelong friendships with famous mobsters, this new anecdote puts a distinct damper on the mood, until we finish dinner. As we

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though our destination—the luxurious marina where Lewis anchors his boat is less than a five-minute walk away.

Earlier that same day we had spent several hours at a photo shoot for Kellogg's, which joined with the M.D.A. in a

promotion for this year's Labor Day-weekend telethon. Lewis wore a white chef's apron, hugged children on cue, and gazed reverently at an oversize box of Rice Krispies. The current national poster child is a tiny frecklefaced redhead named Lance Fallon, and at one point Lance grabbed Lewis's hand and started kissing it with a devotion so passionate it

was almost painful to witness. "Yeowno biting!" Lewis said curtly. He bopped the child on the head with a pad of paper and walked off abruptly. Lance looked confused. Lewis's humor often has a hard edge, and sometimes his smaller fans aren't entirely sure what to make of it. When Lance started bouncing up and down in his seat, Lewis growled, "What did he get for breakfast? A little Ritalin never hurt any kid."

During one lull in the action, Lance and a small black girl began to giggle and squirm. Lewis snapped at them, "We can't have that, children, or you'll be out of the show so quick you'll never know what happened." A slight pall fell over the Kellogg's reps, M.D.A. officials, parents, and other adults waiting around, but Lewis's instincts are finely

honed; raising his voice so everyone could hear him, he added quickly, "Get my traction out of the car so I can hang them!" After all, the Jerry Lewis persona has always included a large measure of hostility, if not outright malice. When another boy introduced himself, Lewis replied, "I'm Jerry. How old are you?" The kid said he was nine. "You're nine? So am I. Let's go outside and throw a rock in a window," Lewis suggested.

Later, inside his stretch limo on our way back to the boat, his voice rose in a stirring denunciation of those who fail to give their all in support of his "kids." I could see the veins pounding in his temples. But then, as if observing his own performance, he caught himself, "Wasn't that great?" he asked.

"Didja like that? Good energy, huh?" He pressed a button and the window of the limo slid down. Lewis leaned out with a fixed smile on his face and started waving like an automaton. "Hi... Hi...Hi...," he said. The sidewalks



"I told her, 'If you do anything to hurt my kids, I'll have you killed, you understand? I'll have you killed.' "



Top, Los Angeles activists picket Lewis and the M.D.A. for perpetuating stereotypes of the disabled. *Above*, Evan Kemp Jr., former chairman of the Equal Employment Opportunity Commission, who says the M.D.A. hired a man to spy on him.

were full of passersby, but nobody seemed to notice. Block after block, he kept it up, waving as if ours were the lead car in a motorcade, except that there were no squeals of recognition or delight from the crowd.

Finally he rolled the window back up and lapsed into a sullen silence. J.L. does not like it when no one is paying attention. He is 67 years old, and he has been in show business since he was five, but he will still go to any lengths to draw the spotlight to his corner of the stage.

This is a man who spent his entire adult life shoving microphones and pickles and chow mein up his nostrils to get a laugh. He hasn't changed a bit. The next night we're in a different restaurant with a bunch of his friends, at a table for eight, and at one point everyone is occupied talking to someone else, and no one is looking at J.L. He picks up a roll, shreds it, and packs the crumbs into his mouth until it is stuffed too full to close. Then he pretends to choke. His wife turns; she is well trained. An indulgent smile on her face, as if she were humoring a small child, she pats him on the back. By now all eyes are on J.L. He grins and opens his mouth. Each time his wife taps his back, breadcrumbs spray from his mouth and cascade down the front of his clothes. Everyone laughs, J.L. spews some more bread-

crumbs from his mouth. He looks like a leaf blower in overdrive. By this time people at other tables are watching, too. When he finally runs out of breadcrumbs, he flashes a dazzling grin. His audience

smiles. He nods magisterially, as if acknowledging his grateful subjects. Attention has been paid. He looks serene and satisfied. For the moment at least, Jerry Lewis is a happy man.

he palm trees rustle gently in the balmy breeze that caresses San Diego Bay. Vivid flowers are blooming in carefully manicured pots around the marina, which is thick with boats of every description, all gleaming white in the morning sunshine. Gleaming the brightest of all is Sam's Place, Lewis's 68-foot Grebe motor yacht, a pristine beauty of polished teak that sports thick red carpeting inside. Sam (short for SanDee) is Jerry's wife, the former dancer he wed after divorcing Patti, the mother of his six sons, to whom he had been married for 36 years. Jerry's Place, a second boat tied up alongside the big one, is a 16-foot Boston Whaler.

Inside the boat, coos and gurgles emanate from the next cabin, where Sam is taking care of Danielle, the baby girl the Lewises adopted last year. The family lives in Las Vegas, but they spend several months a year on the boat, even though they apparently don't take it out on the water very often. For J.L., just sitting there at the dock seems to be enough. "You can't explain boat peo-

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ple," he tells me with a lofty shrug. Despite open-heart surgery in 1983 and a bout with prostate cancer last fall, he looks tanned and robust.

We are talking about anger. Lewis, who has been described as having "three rows of teeth," is famous for his. "At least I'm a good boy now—I don't use my hands," he says with a shrug. In the old days he used to haul off and hit people with a kind of vengeful glee. "At the moment you do it, it's wonderful," he recalls wistfully. "Watching a guy go on his ass—particularly when it's "Why should a Jew get his car before anybody else?"—it's wonderful to see him hit the deck."

Lewis had acquired his first ulcer by the time he was 30, and during the 1970s, when his Percodan addiction masked the symptoms, he came within two weeks of bleeding to death before a more dangerous ulcer was discovered, according to his doctor. Jerry Lewis has never been what you might call a laidback individual. It does not take a rocket scientist to figure out why he has been so angry all his life, but when I ask him what he sees as the original source of his rage, he looks startled, as if he had never thought of this before. "Maybe the original source of the anger was... abandonment?" he suggests, as if trying to guess the answer to a multiple-choice quiz. Oh yeah, abandonment. This is, after all, the only child of two vaudevillians who were on the road more than half of every year, who were always stashing their heartbroken son with relatives while they went off for weeks at a time; these were parents who managed to miss their own son's Bar Mitzvah, although they did telephone to say mazel toy. Lewis, or Joseph Levitch, as he was then known, was a little boy who was never sure his parents loved him, because they were never there. Every time they left him, "it was a killer," he says brusquely.

However, Lewis has never delved too deeply into his past. Many years ago, during a period of intense emotional stress after his breakup with Dean Martin in 1956, he went to a psychiatrist who advised him not to enter psychoanalysis. "The danger is that your pain may leave, but it's also quite possible that you won't have a reason to be funny anymore," the shrink said. Being funny won.

Although he has always idolized his father, Danny Lewis, whom he credits with teaching him everything he knows, his supposedly inspirational anecdotes about his father's tutelage can be hair-

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raising. One time, he says, "I did the best 90 minutes of my life, and 1 go backstage and look for my dad: Give me my medal, Dad. And he says, 'You were O.K.—for an amateur.'" Lewis shakes his head, wincing at the memory.

Assuming that this incident happened when Jerry was just starting out, I ask how old he was at the time. "Oh, it was about a year before my father died," Lewis says offhandedly. His father died in 1982, which means that Jerry was 55 years old and had been a show-business icon for more than three decades when his dad called him an amateur. "He was right on the money," J.L. assures me. "He knew everything—everything—about the racket."

No doubt that perfectionism paid off; in his heyday, Jerry Lewis was an international sensation. He made his stage

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debut at the age of five, singing "Brother, Can You Spare a Dime" at a hotel on the borscht circuit in upstate New York. Before he was 21 he and Dean Martin were one of the hottest acts in show business. Painful though it was, even their breakup didn't slow Lewis down; in 1959 he signed a \$10 million contract with Paramount Pictures to star in 14 films over a seven-year period. At the time, it was the biggest single transaction in movie history for the exclusive services of one star.

But whatever he did, it never seemed to be enough for his father. When Jerry's parents moved out to California, he got them an apartment in Beverly Hills and a custom-built Cadillac, a one-of-akind luxury sedan that cost him a fortune. He bought 25 yards of red ribbon to wrap around the car, tied a great big bow on the hood, and delivered it to his father's doorstep. His father's only comment was "How come it's not a convertible?"

So who could be surprised that Danny Lewis's son developed a notoriously explosive personality? These days J.L. likes to talk about how much he's changed since his open-heart surgery, his lovey-dovey second marriage (he

calls her "Mommy," she calls him. "Daddy"), and especially since falling in love with his seventh child, who is of course called Danni and who is his first daughter. "After the heart surgery, I had a whole different sense of almost everything," he says. "Room service being late wasn't such a big deal. Little chickenshit things that would annoy you, you were embarrassed at that kind of annoyance now." J.L.'s friends attest to how mellow he's become.

This can come as a surprise if you've ever tried to have a reasonable conversation with him about disability rights and the views of movement activists, many of whom flatly reject the Muscular Dystrophy Association's "pity approach." The spectacle of Lewis, sweating and weeping, begging for the folks out there to fork over

enough bucks to save "my kids" has long struck many observers as distasteful and demeaning. "My kids cannot go in the workplace," he says in a typical appeal. "There's nothing they can do. They've been attacked by a vicious killer. I'm begging for their survival!" Such pity-monger-

ing has seemed especially anachronistic since the Americans with Disabilities Act went into effect last summer. A groundbreaking anti-discrimination law that reflects the current emphasis on mainstreaming the disabled, the A.D.A. promotes the idea of integrating them into the workplace and helping people lead productive lives rather than segregating them as objects of charity.

But old habits die hard, and Lewis has been adamant in refusing to address the concerns of his critics. A year ago a television interviewer asked him if he had ever considered the possibility he might be wrong in his wholesale rejection of the activists' views. "Never, never, never!" Lewis said. He has not re-evaluated this position in the intervening months. Sitting with him now, I ask whether he thinks his detractors make any valid points at all. "None!" he barks. End of subject.

He sees the dissidents as a tiny handful of malcontent ingrates. "You have to remember they're sitting in chairs I bought them," he says nastily, referring to the motorized wheelchairs the Muscular Dystrophy Association helps provide to those who meet certain requirements.

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"This one kid in Chicago would have passed through this life and never had the opportunity to be acknowledged by anybody, but he found out that by being a dissident he gets picked up in a limo by a television station. What do they want me to do? They want me to not raise \$120 million Labor Day? They want me to stop work in the labs? There's 19 of them that are telling me not to raise \$120 million. I don't give a good goddamn what they call it; I am giving doctors money so that your new baby and my new baby never have to deal with this. I must be doing something right; I've raised one billion three hundred million dollars. These 19 people don't want me to do that. They want me to stop now? Fuck them." He watches me write this down, and then says loudly, "Do it in caps. FUCK THEM."

very Fisher Hall is electric with anticipation as the lights go down for the Toyota Comedy Festival, which will mark Jerry Lewis's first appearance in Manhattan in more than a decade. The crowd is clearly expecting a good time. Alan King is the first to welcome the audience ("Good evening, ladies and germs") and to introduce the host as "actor, comedian, director supreme, one of the world's most beloved clowns-Jerry Lewis." Lewis gets a standing ovation before he even speaks. "I am so thrilled," he brays in the loud, nasal, quintessentially obnoxious voice he uses only when he's performing. "I have never been in Eddie Fisher Hall! Being here is a special joy for me, because I have such regard for ... uh ... for ... He checks the inside of his lapel, as if looking for a cue card. "For the Toyota company!" He rolls his eyes.

Actually, Lewis's function as tonight's host is largely an honorary one of introducing the other comics. Richard Belzer, the first on the lineup, acknowledges Lewis as "the King" and adds, "I wanted to be Jerry when I was a little kid. Then I took some medication—and I became me."

Outside on the Lincoln Center plaza, the fountain is splashing gaily in the soft summer night as people in motorized wheelchairs begin gathering quietly in front of Avery Fisher Hall. When the show is over, the departing audience is met with the earnest upturned faces of demonstrators distributing flyers that read, "Disabled People Protest Jerry Lewis Nationwide." Some people accept the handouts; others walk on by. A few are overtly hostile. "Jerry Lewis is



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Jerry Lewis (right) with his former partner Dean Martin. Lewis built his career using a stage persona that now seems a caricature of disability.

a saint!" spits out one middle-aged man. Without directly accosting anyone, the protesters keep offering their message, which accuses Lewis of "pity-mongering" and promoting "outdated stereotypes." They don't seem angry, simply patient and determined.

"I think Jerry Lewis was a fine comedian," says Frieda Zames, a retired college math professor who is vice president of Disabled in Action of Metropolitan New York. "He just doesn't understand our problem with telethons. I think he doesn't have a clue. I don't think he's a malicious man; he's so sure of himself he just doesn't realize that what we're trying to say might have some merit. But it's very hard for us to function in the world with this image of disabled people he puts before the public. We're trying to become part of society. Disabled people want jobs, want to be part of the community, want to participate. And at some point we have to say we can't be put down in order to get what we should have. It's not a fair exchange to

say you have to lose your dignity in orderto get the appliances you need."

Before 1990, a lot of people weren't thrilled with Lewis's approach, but most kept their doubts to themselves. Then came an infamous cover story he wrote for Parade magazine, displaying a sensibility that seemed several decades out of date. He referred to disabled people as "cripples" and called dystrophic illness "this curse that attacks children of all ages." Trying to imagine what the life of a disabled person is like, he put himself in a wheelchair and decried the source of so many people's mobility as "that steel imprisonment," bemoaning how "trapped and suffocated" he felt. "I realize my life is half, so I must learn to do things halfway," he wrote. "I may be a full human being in my heart and soul, yet I am still half a person."

The article was greeted with horror and incredulity by disability-rights activists. "My wheelchair isn't an imprisonment—it's a tremendous vehicle of liberation." says Carol Gill, president of the Chicago Institute of Disability Research. "What's a

steel imprisonment is those negative images that Jerry Lewis and the M.D.A. promote. The stereotypes keep us locked in a cell of discrimination and prejudice."

"I used to think the telethon was harmless, until the Parade article," says Cris Matthews, a former Muscular Dystrophy poster child who is now 38. "It was like running into a brick wall: all of a sudden we realized the harm it was doing. They have a spokesperson who thinks he's the god of disability, and he just totally misrepresented what we've spent our lives fighting for, which is the idea that our lives are worthwhile and that they could be functional. He painted the worst picture of disability you could paint. It was like 'I would rather have my child dead than have dystrophy.' My brother and I decided we had to do something about this. Jerry Lewis has to go. He has no right to do this to anybody's life.'

With her brother Mike Ervin, who is also a former M.D.A. poster child, Matthews formed a Chicago-based group called Jerry's Orphans. "It's a sarcastic shot at that mentality," explains Ervin, a 37-year-old freelance writer who happens to be the "kid in Chicago" Lewis denounces. "I think the term 'Jerry's

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Kids' is insulting and antiquated, and counterproductive to anything but the M.D.A.'s fund-raising purposes. It reinforces the childlike stereotype; it infantilizes and emasculates people with disability."

Lewis himself uses "Jerry's Kids" as a term of endearment, and he does so without embarrassment or irony. We are sitting around his boat one afternoon when the telephone rings. "One of my kids," Lewis mouths to me as he takes the call. After he finishes, he tells me the caller was Stephen Mikita, an assistant attorney general of the state of Utah. "He's an incredible kid," Lewis assures me. "I deal with him as I deal with all my kids: I will not talk down to them. His greatest joy is to hear me say, 'I'll race you to the corner-and you're going to lose!' because nobody else does that."

Mikita is 37 years old, but he doesn't mind Lewis's terminology at all. "My dad calls me one of his kids, too," Mikita says. "With Jerry, I think it's evidence of the passion. That term is indicative of the almost familial commitment he has. I think it shows how much he truly cares—as much as a father or grandfather cares about his children and grandchildren."

Nor does Mikita have any doubt about Lewis's stature. "Jerry Lewis is one of the greatest humanitarians who has ever lived," he proclaims. "He's one of my heroes in life—Jerry and F.D.R. Jerry Lewis spoke about persons with disabilities, and embraced persons with disabilities, long before it was politically correct or in vogue to do it."

Like Mikita, there are many people with dystrophic illnesses who are proud to be considered "Jerry's Kids" and who disagree vehemently with his critics. "I don't know of anyone else who puts the time, caring and love into efforts against this disease the way you do into the Telethon," one parent wrote in a letter published by the M.D.A. "So if you have to beg, borrow or steal, make people cry or shake their heads, too bad! Our kids need everything you get for them. Please know that the people who need you and the people who love you are behind you 100 percent!"

However, others see a more insidious message in Lewis's approach. "Four major annual telethons—Easter Seals, the Arthritis Foundation, United Cerebral Palsy, and the M.D.A.—are the single most powerful cultural mechanism defining the public identities of

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people with disabilities in our society today, mainly because they reach so many people," reports Paul Longmore, a historian who teaches at San Francisco State and who has specialized in the history of people with disabilities. "The telethon sponsors claim that, collectively, they have a combined audience of 250 million people. That's the equivalent of the population of this country. The message of telethons is that whatever condition people with disabilities have, that condition has essentially spoiled their lives, and the only way to correct that is to cure them. The message of the disability-rights movement is that it's possible to be a whole person with a disability."

The disability constituency is vast; according to government figures, 43 million Americans are defined as disabled

### "What my wife and I saw frightened us. I'm not prepared to take on Jerry and the boys."

in one way or another. Although their views vary widely, many see Lewis's intransigence as proof that he has outlived his usefulness, although they acknowledge the contribution he has made over the years. "Jerry Lewis's approach is a relic of the past," says Laura Hershey, a Denver activist who helped organize the Tune Out Jerry Coalition. "There's still a sentimental feeling about him because he's been working at it for so long, but the kind of approach he's using doesn't have any place in how our community feels about itself now."

The curious thing is that Lewis has shown no inclination to accommodate the evolving consciousness of the group he has dedicated so many years to helping. Many disabled people now object to some of the language commonly applied to them, and these days one is likely to be corrected if one uses a loaded term like "polio victim" the preferred phrase is "post-polio" or describes anyone as "suffering" from muscular dystrophy. "I don't suffer," Mike Ervin retorted on the air to one unenlightened television interviewer last year.

"Jerry Lewis grew up at a time when 'crippled' was the word generally used to describe people like us," explains Dr. Arnold Gale, a pediatric neurologist and

a member of the M.D.A.'s National Task Force on Public Awareness. "That gave way to 'handicapped,' which was replaced by 'disabled,' which then became 'physically challenged,' and now in some corners they're even going back to 'cripple.' People are confused about what they're supposed to say."

To some, such shifts reflect the tyranny of political correctness, and it is possible to view Jerry Lewis as its casualty. On the other hand, it is hard to dispute that routinely defining an entire class of people as childlike, dependent victims might affect the dignity and respect they are accorded in the workplace. Moreover, Lewis continues to make inflammatory pronouncements. If you found out you had amyotrophic lateral sclerosis, "you might as well put a gun in your mouth," he said on the 1991

telethon—a statement that hardly improves societal attitudes toward people who continue to lead productive lives despite that diagnosis.

But what is most surprising is Lewis's reaction to any criticism, which is so hostile and paranoid it seems almost Nixonian. It

would have been fairly easy, and certainly desirable from a public-relations standpoint, for Lewis and the M.D.A. to defuse the attacks by meeting with opponents, paying lip service to their points, and making a few substantive changes. Instead, they have responded with astonishing virulence. One of their earliest critics was Evan Kemp Jr., a Washington attorney who has a form of neuromuscular disease and who has long been a leading disability-rights activist. As early as 1981, Kemp wrote an op-ed column in The New York Times voicing his dismay at the telethon's approach. Ever since, the M.D.A. has considered him public enemy number one, and according to Kemp it has gone to extraordinary lengths to monitor his activities. "The M.D.A. hired a guy to spy on me in 1981," reports Kemp, whose parents were among the original founders of the M.D.A.'s Cleveland chapter. "His job was to undermine me on the Hill, He came to Washington and visited me, talked with me, and became my friend. I just thought he'd gotten a job with the M.D.A.; I didn't realize they'd hired him to do this. He finally told me. I really didn't suspect it at all. He also claimed they spent \$250,000 spying on me. That was his sole job. That's a lot of money." The alleged spy, who has muscular

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dystrophy, will talk about the M.D.A. only on the condition that he not be identified. "What my wife and I saw frightened us," he says. "I'm not prepared to take on Jerry and the boys. They would try to destroy me. What little I have, they would try to take it away."

However, he confirms much of what Kemp says, including the fact that he spent almost a year being flown around the country and wined and dined at M.D.A. expense, although he says he was not on salary

and doesn't remember the \$250,000 figure. "I was sent to find out who Evan was, what he wanted, what he and the disabled community were going to do next," he reports. "They told me they felt Evan had cost them \$4 million in contributions, and they wanted to discredit him."

M.D.A. officials deny Kemp's charges as preposterous. "It's not true," says Gerald Weinberg, the director of field organization. "It's a delusion."

But after Kemp succeeded Clarence Thomas as head of the Equal Employment Opportunity Commission in 1990, his opponents renewed their efforts to neutralize him. According to Kemp and his staffers, the M.D.A. orchestrated an intensive campaign to block his reappointment when his term expired, lobbying strenuously at the White House and on Capitol Hill. Weinberg claims that the M.D.A. had nothing to do with this effort and that members of its advisory task force were acting independently in campaigning against Kemp. But Jerry Lewis wrote President Bush an angry letter accusing Kemp of "misusing the power of

his governmental office" by making statements that could hurt the telethon. "If ever there was a point of light...I'm it," he railed in an outburst that was promptly described by a headline writer as "Points of Spite." The M.D.A. also went after Kemp's pocketbook. "They attempted to boycott Invacare, a wheelchair company I helped found, saying I was attacking the M.D.A. and costing them money," Kemp says. "It was ex-



"A lot of the money goes to keep the M.D.A. alive, to keep money in the pockets of its administrators," says Carol Gill. "It's an empire."



Top, Jerry Lewis in the 1950s with his first wife, Patti Palmer, and their son Chris. *Above*, Lewis with his new family, second wife Sam and their adopted daughter, Danielle.

traordinarily upsetting." Although the M.D.A. has denied having sponsored a boycott of Invacare, the organization did suggest that dealers use other sources for equipment and lobby against Kemp with

various government officials. Kemp's future at the E.E.O.C. became a moot point when Bush lost the 1992 election, and Kemp has since left the agency for the private sector. However, he is not the only activist to be targeted.

Dianne B. Piastro, who writes a syndicated newspaper column called "Living with a Disability," began to publish columns critical of Lewis, the M.D.A., and the telethon after Lewis's unfortunate *Parade* piece. In a scries of articles, Piastro not only deplored the "pity approach" but also raised questions about M.D.A. finances, including high executive salaries, unexplained expenses, and the organization's frequent failure to make available some of the financialdisclosure forms required by law, detailing how it spends the massive amounts of money raised every year. (Last year's

revenues exceeded \$100 million, but the organization still came up short with a \$6.4 million deficit.) Although Piastro has repeatedly requested interviews with M.D.A. officials and even submitted written questions, the M.D.A. has stonewalled almost all

of her inquiries. "Why would anybody respond to unjust criticism?" asks Weinberg, who describes Piastro's columns as "erroneous and inflammatory."

But the organization's response went further: the M.D.A. threatened Piastro and her syndicate with lawsuits and pressured newspapers not to publish her columns criticizing the M.D.A.

"We intend to take legal action against Ms. Piastro and her syndicator," warned Robert Ross, the M.D.A.'s executive director, in a letter sent to newspapers carrying her column. Despite a couple of years of threats, the M.D.A. never did file suit. Piastro's explanation is simple: "There is nothing actionable in those columns." However, the M.D.A.'s strategy apparently had a chilling effect; many newspapers did not print her subsequent column on the organization. The M.D.A. also encouraged Lewis loyalists to mount a letter-writing blitz, and according to Piastro it even released her home address. (It has also published business addresses to promote letterwriting efforts attacking Cris Matthews, Mike Ervin, and Laura Hershey.) Piastro was especially perturbed by the exposure of where she lived. "I really

#### Letter from Las vegas

felt vulnerable," says the columnist, a 54-year-old grandmother who has multiple sclerosis and gets around in a wheelchair. "I must admit, when I went out to walk the dog at night I'd look both ways."

The effect of such tactics is hard to assess. "I'm not really sure" how much impact the M.D.A. campaign had, Piastro says, but her fate was exactly what the M.D.A. might have wished: her syndicate, the Newspaper Enterprise Association, recently declined to renew her contract. (Diana Loevy, the executive editor of the N.E.A., denies that the decision had anything to do with the M.D.A.'s pressure tactics, attributing it to the fact that Piastro's column has a "specialized" audience-something the N.E.A. could presumably have deduced before it signed her up in the first place.) Other M.D.A. critics have also suffered harassment. The M.D.A.'s lawyers, while denying that they were impinging on Cris Matthews' right to free speech, nevertheless threatened her with legal action in retaliation for the Jerry's Orphans protests, warning that she and anyone working with her would be held "personally and financially responsible for any and all losses" the M.D.A. might suffer. When the M.D.A. closed a summer camp in the Chicago area, those who complained were told to blame Matthews and Ervin for hurting the organization's fund-raising ability.

The spectacle of a big-business behemoth like the M.D.A. expending valuable resources to crush opposition among the very disabled people it purports to serve is so bizarre it seems surrealistic. Moreover, the M.D.A.'s continuing characterization of its critics as a tiny handful of mean-spirited rabble-rousers simply indicates to many others how out of touch the organization is with its ostensible constituency. "There is a real dispute between the disability rights movement and the MDA that goes far beyond Evan Kemp and his relatively mild statements about 'the pity approach,' " wrote Deborah Kaplan, director of the division on technology policy at the World Institute on Disability, in a letter to the White House last year. "Whether or not the MDA wishes to acknowledge it, there is very broad support from disability advocates for the position that Evan Kemp has taken and for his right to express his views. I can assure you that this is not an issue that has been manufactured by Mr. Kemp.... The pity approach does not encourage 'mainstreaming' or civil rights for persons with disabilities....

The fact that the MDA fails to acknowledge that these expressions are genuine and are based on our experiences as persons with disabilities is disappointing and insulting."

The M.D.A. is clearly frightened by any criticism; these are hard times for telethons, and the future is uncertain. The M.D.A. telethon currently draws 80 million viewers, a decline of at least 10 million over the last few years, a drop M.D.A. officials attribute to shrinking network audiences. However, last year's telethon take was nearly \$45.8 million, the highest ever, despite the charges by M.D.A. officials that their critics are hurting fund-raising efforts. Oddly, however, even while Lewis and his fellow M.D.A. officials continue to insist that the protesters have no legitimate opinions whatsoever, the organization

### When Lance started bouncing up and down, Lewis growled, "What did he get for breakfast? A little Ritalin never hurt any kid."

has quietly made changes that seem to constitute at least a token response to their charges. Instead of focusing primarily on doomed children, the last telethon pointedly featured functioning adults, including Steve Mikita as the recipient of the first National Personal Achievement Award in recognition of his professional success, personal leadership, and community service.

"It doesn't seem coincidental that these changes have come at a time when there's this mounting negative reaction from the disability community," observes Paul Longmore. Nevertheless, not only do M.D.A. officials claim their critics have had no impact—"None whatsoever," maintains Weinberg—they even deny there have been any changes.

The M.D.A.'s antipathy toward criticism is not hard to understand; big bucks are involved, not only for the charity's beneficiaries but also for its officials like Robert Ross, the executive director, whose salary exceeds \$288,000 a year. This made him the third-nighest-paid executive among charity bosses surveyed last year by *Money* magazine. Moreover, Ross's compensation looks even higher when assessed against an important standard set by the survey: "'If a

charity functions primarily as a middleman, handing out funds to other groups that actually do the research . . . the leader is typically paid less than if the charity itself provides such services," Money stated. Although the M.D.A. dispensed \$19.6 million to research on neuromuscular diseases last year, it functioned as a middleman rather than actually conducting the research. By comparison, the responsibilities of the highest-paid executive on the Money list, City of Hope's Sanford Shapero, include the direction of a medical center and a research institute in addition to a fundraising organization.

Nevertheless, *Money* named the M.D.A. to its "honor roll" of the 10 best-managed large U.S. charities, and the organization did measure up well according to some of the survey's other

criteria. Money gave its approval to charities that spend at least 65 percent of their income on program services rather than fund-raising and other costs, and 82.5 percent of the M.D.A.'s expenses go to program services, including research, with only 17 percent allotted to fund-

raising. However, the financial reports filed by such charities often leave significant areas impenetrably vague, and the M.D.A. has shown little enthusiasm for clarifying the mysteries. "Who used the travel money and what type of travel did they do for the \$6.9 million spent in 1990?" Dianne Piastro asked the M.D.A.'s director of finance in a written query two years ago. She has never received an answer.

"A lot of the money goes to keep the M.D.A. alive, to keep money in the pockets of its administrators," says Carol Gill. "It's an empire. They are big business, and it's a business that exploits people with disability. They don't bring us in and say, 'How can we do this better?" They have a few token people on the board, but the activists who have fought for our rights get threatened."

Although M.D.A. officials consider such charges unfair, their recordkeeping seems inadequate to refute key points. The M.D.A. board contains only two disabled people out of 20, according to Weinberg (most of the disabled are relegated to an advisory task force), and the organization is unable to provide figures on what percentage of its staff is disabled. Jerry Lewis, who has compared the

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protesters to neo-Nazis, presents a more complicated question. Stories abound of his dedication to people with neuromuscular diseases, his unflagging efforts on their behalf, his tireless commitment to the cause as he crisscrosses the country and works the phone lines in support of the disabled. "There probably isn't a day of the year where he isn't doing something for the M.D.A.," attests Weinberg, who has known Lewis for 36 years. What began more than four decades ago as a charitable sideline has slowly assumed center stage in Lewis's life, and today it is clear that his contribution to the fight against dystrophic illness constitutes his life's work. It has always seemed ironic that Lewis, who spent virtually his entire professional career working to help people with neuromuscular diseases, built that very career through a stage persona that was so spastic as to seem disabled, so dopey as to appear retarded. He developed that character very early in life; even in school he was known as "Id," short for the Idiot. Later, when he became famous, the internationally known character named Jerry Lewis often seemed like one endless, increasingly unfunny joke on people who actually had progressive degenerative diseases.

Further irony can be found in the vicissitudes of his success. When Lewis's career was at its height, he surely didn't imagine that the time would come when generations of younger people who never knew him as the world's most famous comedian would someday recognize him primarily as the guy who sings "You'll Never Walk Alone" off-key every Labor Day. To be sure, the telethon has long since assumed the status of a camp classic, and in some circles it has even inspired a cult following among those who gather to hoot at the parade of hasbeens and never-weres who predominate among telethon guests. To the callow young, the name Jerry Lewis conjures up less-than-reverential images. "You know why I like Jerry Lewis?" said Guardian Angel Curtis Sliwa on his New York radio show last year. "He still uses Brylcreem and Wildroot. He's one of the last, right? I mean, talk about 'greasy kid stuff'! Mickey Rourke must have learned hair-conditioning treatment from Jerry Lewis."

Like his hairstyle, Lewis's career hasn't exactly been on the cutting edge lately. His one-man show is so tired it seems to have been caught in a time warp: there are Polack jokes and Jew jokes, Chinese jokes and Jap jokes, rab-

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bi jokes and priest jokes, toilet jokes and penis jokes. The only new element is Danni, who is hoisted onto the stage at the end of the show, long past a baby's bedtime, blinking in the harsh glare of the spotlight; her face crumples and she begins to cry. When Lewis played the Westbury Music Fair on Long Island recently, the opening act was comic Pat Cooper. "My God-Sunday night in Westbury," Cooper said sarcastically. "Who knows-maybe next year, Utah!" But high-profile work is harder to come by these days, even at home in Las Vegas. "Years ago I used to play 20 weeks a year in Vegas," Lewis says sadly, "I didn't have more than four weeks last year."

Although he has earned many millions of dollars over the years, he has also spent lavishly and made some

"If I went down Fifth Avenue window-shopping and no one bothered me, it would break my heart," Jerry Lewis said.

catastrophic business decisions. The most traumatic failure was that of the Jerry Lewis Cinemas, a chain of family-oriented movie theaters that was forced into Chapter 13 in 1981. "You never can recoup that kind of loss," he says. "We're talking \$50 million. It took my entire career to have that free and clear." He adds proudly that he paid off all his creditors, "but it cost me everything I had. I was tapped."

He says he has accepted his reduced circumstances. "You drive one car, you eat three meals, you kiss Danni 7,000 times a day-what else do you need?" he says with a shrug. "As long as all my responsibilities are taken care of, I'm fine." However, although his current lifestyle would indicate he's not exactly destitute, it's hard to decipher where the money comes from. Lewis has always made much of the fact that he takes no salary from the M.D.A., but he travels constantly on M.D.A. business, and stretch limos seem to be de rigueur. M.D.A. officials say that many of the perks are donated and cost their organization nothing, but they are unable to provide figures on how much Lewis's expenses amount to per year. "I have no way of knowing what that figure is," Weinberg claims.

Lewis himself has always been indignant about questions concerning his compensation, attributing them to the post-Watergate cynicism of an overly suspicious press. He is proud of his contribution and he says he has no regrets. But whatever peace of mind he has achieved, the old themes resurface inexorably. There is the anger, and there is the need. One night my phone rings and it is J.L. He has just learned that I have interviewed Evan Kemp, and he is furious. "Evan Kemp is a vicious, poisonous individual," he hisses. "If I had known you were going to talk to Evan Kemp, I would never have talked to you!"

I tell him I am amazed he would ever have imagined I could write about

him without interviewing Kemp; it is, after all, a reporter's job to explore every point of view in a controversy, and the former chairman of the E.E.O.C. is Lewis's most prominent critic. J.L. is not mollified. "It just kills me to think about these people getting publicity," he rages. "These people are leeches.

They all glommed on to being Jerrybashers. What did they have before that? They're disabled people who are so bitter at the bad hand they were dealt that they have to take down somebody who's doing good. There's 19 of them, but these people can hurt what I have built for 45 years. There's a million and a half people who depend on what I do!''

The voice on the other end of the phone is the powerful one of the 67year-old man, but inside it I hear something else, something faint but as persistent as an echo that follows you wherever you go. It is the pain of the angry little boy, and I suddenly realize that the message delivered by the protesters is the one he has heard in his nightmares all his life: They don't love you. No matter how much you try to do for them, they don't love you.

Despite all the decades of acclaim, the craving hasn't abated; J.L. may have kicked Percodan, but he will never kick the need for adulation, something he admitted to me weeks ago. "If I went down Fifth Avenue window-shopping and no one bothered me, it would break my heart," he said. The look on his face was enough to break mine. □