Sunday

Partly cloudy
High 82, low 57
Details on Page 44A


Cheese steak chomper

TASTY

The local flavors of Chicago, Philly

Travel, Section G

TMS RACE WEEK PREVIEW

A special section previews the upcoming NASCAR events at Texas Motor Speedway: the Albertson's 300 in the Busch Grand National series on Saturday and the DIRECTV 500 in the Winston Cup series on Sunday, April 2.
Section Q

NCAA MEN'S TOURNAMENT

MIDWEST REGION FINAL: Michigan State 75, Iowa St. 64
WEST REGION FINAL: Wisconsin 64, Purdue 60

NCAA WOMEN'S TOURNAMENT

MIDEAST REGION SEMIFINALS: Texas Tech 69, Notre Dame 65
EAST REGION SEMIFINALS: Connecticut 102, Oklahoma 80

Coverage, Pages 1, 10-12, 14B

The Dallas Morning News

Texas' Leading Newspaper | Dallas, Texas, Sunday, March 26, 2000 | www.dallasnews.com | $1.50

Clinton presses Pakistanis to pursue democracy, peace

He warns regime to curtail arms race, India dispute

By G. Robert Hillman
Washington Bureau of The Dallas Morning News

ISLAMABAD, Pakistan — President Clinton, in an extraordinary bit of personal diplomacy Saturday, urged the Pakistani military regime to restore democracy and move away from the violence of Kashmir and the prospect of nuclear war with India.

In private meetings with Gen. Pervez Musharraf and in an evening television address to the Pakistani people, Mr. Clinton sought to bring Pakistan back into a new network of nations.

"Like all key moments in human history, this one poses some hard choices," the president said on state-run television. "For this era does not reward people who struggle in vain to redraw borders with blood."

Pakistan was the president's last stop on a weeklong tour of South Asia that also took him to India and Bangladesh. And it was a stop cloaked in some of the heaviest security of his presidency. He abandoned the huge, gleaming blue-and-white Air Force One and arrived in a small, plain white jet with no markings at all — just a tail number.

"We took a number of additional security precautions for our trip here," White House press secretary Joe Lockhart said in Islam-

Please see CLINTON on Page 31A.

OSCAR'S STAGE IS SET

Hollywood basks in a golden glow Sunday, thanks to Oscar and his gilded cronies. We've got everything you need to know about the movies' big day:

- **THE POLITICS:** Long criticized for conservatism — despite the low-cut dresses and wild acceptance speeches — the Academy Awards has a distinctly progressive bent this year. A look at the politics of Oscar, a full-page scorecard and more. **The Arts, Section C**
- **LIVE AND ONLINE:** Look for a flood of features plus updates during the show on our Web site, **www.guidelive.com**
- **THE SHOW:** Billy Crystal will be back in the saddle as host when the festivities kick off at 7:30 p.m. on WFAA-TV (Channel 8). **TV Week**
- **BEST CAMPAIGN MOTION PICTURES:** In The Running, **Page 18A**
- **OSCAR PREPARATIONS:** Overnight, **Page 42A**

Tougher rules for City Council endorsed in poll

Majority favor ethics-review panel, salaries

By Michael Saul
Staff Writer of The Dallas Morning News

Three-quarters of Dallas residents support the major provisions of a proposal to strengthen the city's ethics code, and a majority trust few or none of their City Council members to police themselves, according to a poll commis-

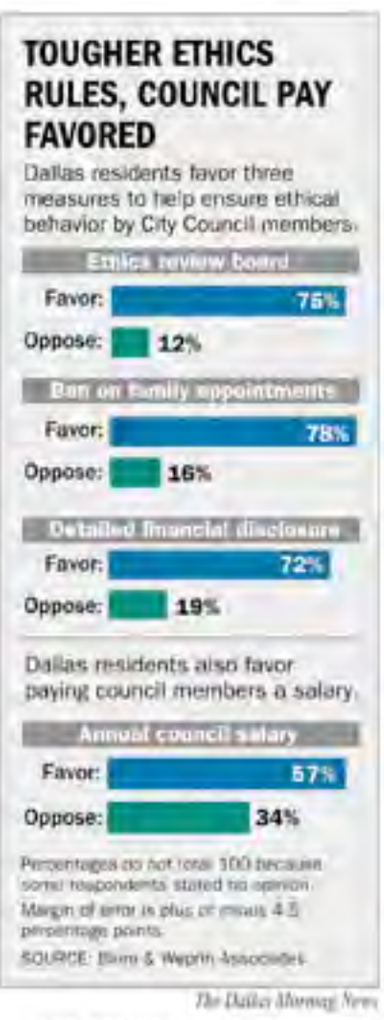
sioned by *The Dallas Morning News*.

The poll found that residents — across racial, geographic and economic lines — overwhelmingly favor the creation of an ethics review board to hear complaints against council members and other city officials.

Residents also believe that council members should be prohibited from appointing immediate family members to city boards and should be required to complete the same financial disclosure forms as state legislators, the poll shows. Those forms are significantly more detailed than the ones council members fill out today.

TOUGHER ETHICS RULES, COUNCIL PAY FAVORED

Dallas residents favor three measures to help ensure ethical behavior by City Council members.



Percentages do not total 100 because some respondents stated no opinion.
Margin of error is plus or minus 4.5 percentage points.
SOURCE: Blum & Weprin Associates

The Dallas Morning News

And, perhaps indicating a significant change of heart among Dallas residents, the poll found that 57 per-

Please see TOUGHER on Page 30A.


The Dallas Morning News Allison V. Smith

Now almost 12, Ryan Dant plays second base at baseball practice three times a week. When his Hurler-Scheie syndrome was diagnosed in 1991, most victims didn't live past age 10.

THE GIFT OF A FUTURE

Foundation improves outlook for boy by investing in treatment for rare disease

By Tony Hartzel
Staff Writer of The Dallas Morning News

CARROLLTON — Ryan Dant is an ordinary boy who wants to live an ordinary life with an unordinary disease.

Doctors couldn't see the boy's future past age 10. Sometimes, neither could he.

"Dad, what's it going to be like when I die?" he would ask while lying next to his father.

"I would tell him that he wouldn't have . . . [the disease], and he can play baseball all the time," said his father, Carrollton police Lt. Mark Dant. "I'd say, 'When you're in heaven, your dog Patty will be there because that makes you happy.' "

Thanks to remarkable fund-raising efforts in North Texas that helped scientists develop a new treatment, Ryan soon will turn 12. That's about two years longer than children with Hurler-Scheie syndrome generally live.

When Ryan's condition was first diagnosed in 1991, Lt. Dant and Ryan's mother, Jeanne, knew that drug researchers in California were close to a breakthrough. Ryan's body cannot produce an enzyme that helps clean out certain sugar molecules from cells, which leads to damaging deposits in joints

Please see THE GIFT on 28A.


The Dallas Morning News Allison V. Smith

Ryan misses one class a week to receive an experimental intravenous treatment at the University of Texas Southwestern Medical Center at Dallas.

The Beat goes out

Growth of dot.coms altering San Francisco

By Doug J. Swanson
Staff Writer of The Dallas Morning News

SAN FRANCISCO — The city can be tough on old bohemians, but it's a wonderful town if you own bohemian.com.

Witness for the persecution is "Diamond Dave" Whitaker, 63, who remembers the late 1950s as a time of smoking dope with Beat legend Jack Kerouac and reading hip verse with Allen Ginsberg.

His current struggle, he said: resisting eviction from his rented warehouse space by those who want to move an Internet company in. "Here I am, the last of the Beats," he pronounced, "being pushed out so they can put in some machines."

At a different converted warehouse, just a few miles away, Mark Silva contemplated a brighter future. Behind him was a view of the bay that might, under different circumstances, inspire poetry.

And on the financial horizon lies an initial public stock offering for the Web company Mr. Silva recently founded, which could mean big money. "It's a gold rush," he said.

San Francisco now finds itself in another one of its epochal shifts. In the past the city has been shaped by forces ranging from gold prospectors to earthquakes to robber barons to the Summer of Love. The Beats had their moment, too.

But this time it's the dot.com techno-riche crowd, who are bringing wealth to precincts long without it.

Hundreds of small Internet com-

Please see SAN FRANCISCO on Page 12A.


Ted Turner

Turner keeps till open to bolster U.N.

Foundation has poured millions into programs

By Jim Landers
Washington Bureau of The Dallas Morning News

WASHINGTON — Ted Turner is a dedicated internationalist. The founder of Cable News Network flies the United Nations flag at CNN headquarters in Atlanta. He banned CNN editors and correspondents from using

the word *foreign* unless it is someone's formal job title.

"I've got customers all over the world," he said.

In 1997, Mr. Turner sold CNN to Time Warner and became one of the richest men in the country. He was so rich, and so mad about U.S. arrears to the United Nations, that he wanted to buy $1 billion of the debt and sue Congress for repayment.

You can't sue Congress, his lawyers told him. So Mr. Turner decided to give $1 billion to

Please see TURNER on 24A.

INSIDE

Pope in Nazareth

A weary Pope John Paul II traveled the ancient streets of Jesus' boyhood town Saturday and celebrated Mass in the soaring Basilica of the Annunciation.

International, Page 11A

Tree of memories

On a rainy night near White Rock Lake, a car carrying three teenagers slammed into a tree and spun into the park. In seconds, a couple's passion for life — and for each other — was cut short.

Today, Page 1F

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THE GIFT OF A FUTURE

Continued from Page 1A.

and vital organs.

But the California scientists lacked the money to bring a new drug to the market, estimated in this case to be at least $6 million.

That didn't stop the Dants and a core group of co-workers and friends. Their first bake sale raised $372. When cookies and cupcakes no longer raised enough, they put change jars at gas stations. They even tried the lottery.

As the boy's hands grew too stiff to hold a baseball bat, the nonprofit Ryan Foundation forged ahead. Staying up until the wee hours many weeknights, supporters organized Dallas-area golf tournaments. The first attracted 80 players and raised $28,000. The last, in 1998, drew 400 and netted $151,000.

The Dants' dedication attracted the foundation's largest contribution: $500,000 from a Dallas donor who wishes to remain anonymous.

With $1 million from North Texas in the bank, the California scientists developed a promising treatment that has given hope to Ryan and thousands of families worldwide.

"The fund raising was the difference between the project living or dying," said Dr. Emil Kakkis, who in the early 1990s conducted research on enzyme therapy at the University of California at Los Angeles. "We had very little money, and the project was stalled."

The U.S. Food and Drug Administration regulates medicines to improve public health by keeping unsafe drugs off the market. But the nature of that lengthy and costly development process can keep new treatments from reaching patients in time.

On Tuesday, Lt. Dant will travel to Washington, D.C., to tell FDA officials and congressional leaders about the need to speed government approval for drugs such as the one helping Ryan. The boy is one of 10 children nationwide in the clinical trial, all of whom receive the treatment for free. The FDA just ordered a study that will push back approval to late 2001 or 2002.

"That's way too long," Lt. Dant said. "In the meantime, most of the other kids with this who are really ill will die."

Ryan has responded well to the experimental treatment. He harbors dreams — now attainable — of getting a job, driving a Volkswagen Beetle and going to college.

"I want to do a lot of stuff," the fifth-grader said proudly between basketball games on his school playground. He also now plays second base at baseball practice three times a week. "I want to be a veterinarian — or a baseball player."

The benefactor who wishes to remain anonymous said North Texas community support for the Dants — which came, in part, from publicity generated by a 1992 article and subsequent columns in *The Dallas Morning News* — made the decision to donate $500,000 a natural one.

"It's been one of our favorite causes," she said. "This one is so tangible. And what could be more special than the life of a child?"

Early signs

In 1991, a family pediatrician first noticed something wrong with 3-year-old Ryan when he had a protruding stomach. Specialists at Children's Medical Center in Dallas told the Dants that Ryan suffers from a form of mucopolysaccharidosis, commonly known as MPS or Hurler-Scheie syndrome.

The genetic condition affects about 40 newborns nationwide each year. Without the enzyme alpha-l-iduronidase, most children eventually die of heart failure or pneumonia.

"It's a slow, steady, progressive decline," Dr. Kakkis said. "It's very tough to be a parent of a child with this problem."

Shortly after diagnosis, Ryan began to falter. His fingers began to curl inward as deposits collected on tendons and ligaments. Breathing became difficult.

"As he got older, he'd have difficulty walking long distances, and it was hard for him to get up in the morning," said Mrs. Dant, who works for an airline-reservations company. "He just really slowed down."

Baseball became a lesson in perseverance. By age 5, Ryan had difficulty gripping a bat. His fielding and throwing skills gradually declined. By the time Ryan was 9, his hands were too stiff to swing a bat, and he couldn't fully extend his arms.

But his love of the game was so strong that Lt. Dant gave him a Velcro bat and gloves. When he got a hit, Ryan would race to first base unable to drop the bat stuck to his gloves.

Then one day, while playing soccer, Ryan collapsed on the field in extreme pain. Doctors discovered that his swollen liver and spleen — 2½ times the normal size — had forced a hernia that required surgery.

Before age 10, Ryan had undergone eight surgeries, including a tonsillectomy, two hernia procedures and carpal tunnel syndrome surgery on both wrists. Doctors also recorded spinal fluid pressure eight times higher than normal, which required the boy to endure a spinal tap. Headaches caused Ryan to vomit and pass out.

Then he had to hang up his cleats in 1997. His father would drive the long way around parks so Ryan wouldn't see other children playing.

With so many physical problems, he began to withdraw.

"People sometimes make fun of me when I tell them," he said. "I just say I have a disease."

As Ryan got worse, Lt. Dant faced a decision: Should he spend more time with his ill son or continue the time-consuming Ryan Foundation work?

About three times a week, Lt. Dant would leave his sleeping son at 9 p.m. for a friend's home. There, he and as many as 14 people, including Carrollton police Detective Jerry Pomposelli, would stay up until 3 a.m. writing fund-raising letters and organizing golf tournaments.

Small donations in the first few tournaments from such companies as Adams Golf grew to $25,000 in 1998.

Help came in mysterious ways, too. As one tournament neared, Lt. Dant couldn't find enough golf balls. He came home one day to find 30 dozen golf balls on his front porch.

How did a police lieutenant with no fund-raising experience raise so much money? Perseverance and a 4-foot-2-inch poster boy, Lt. Dant said.

"Companies started realizing that here was a boy who would leave us if we don't work hard to fix it," Lt. Dant said.

Clinical trials

By late 1997, the Dants' glimmer of hope shone brighter than ever. BioMarin Pharmaceutical Inc. in Novato, Calif., announced that it would partner with Genzyme Corp. to spend at least $6 million on research for a treatment, on top of the $1 million donated by the Ryan Foundation.

Dr. Kakkis, the UCLA researcher, joined BioMarin and brought the enzyme-replacement therapy into clinical trials under FDA supervision.

The company, which manufactures the enzyme for 10 patients, took on the project because of the Ryan Foundation's efforts, Dr. Kakkis said.

"There's no greater thrill for me than to see labwork make a difference in people's lives," he said.

One of the 10 families gave Dr. Kakkis a clock. An inscription reads: "You've given us the most precious gift of all — the gift of time."

The Ryan Foundation may host a golf tournament in 2001 to raise money for gene-therapy research. The Dants say they will never be able to thank everyone in full. The money has meant more time for them to enjoy life with their son.

"If they all could just know what they did," Lt. Dant said.

Week by week, drip by drip, Ryan's life improves. The enzyme, while not a cure, has provided hope for a longer, quality life for Ryan.

He misses one class a week for his treatment at the University of Texas Southwestern Medical Center at Dallas, where he has an intravenous solution pumped into his body. In two years, he has grown almost two inches and gone from 61 to 77 pounds, unheard of in children with Hurler-Scheie syndrome.

Ryan has a slight limp because of hip damage already caused by the disease. His curled fingertips will require corrective surgery next month. Other surgeries are likely.

"I'm hoping that I won't get out of breath so easily," he said. "And that I can move my hands better and my fingers will grow."

Ryan's birthday is April 13. He probably would have died or been in a wheelchair and in great pain without the treatment, Lt. Dant said.

"With this disease, it's like all our dreams, one by one, were taken away," the boy's father said. "Now we can actually have thoughts like normal parents."

The Dants never had second thoughts about trying the previously untested therapy. Bone-marrow transplants are an option for some, but they have questionable success and 40 percent mortality rates.

"For some reason, I wasn't nervous with the treatment," Mrs. Dant said. "I felt very good about it."

Improvement was immediate after the first treatments.

"The day we got home, he looked at himself in the mirror and said, 'Look at my stomach, Dad!' " Lt. Dant said, a proud smile on his face. "Before, he didn't want to go swimming because his tummy was too big."

Doctor visits still scare Ryan, who seems to have caught on to medical doublespeak.

"I get scared when the doctors say there's something a little bit wrong," he said. "I think they're going to have to do something to me."

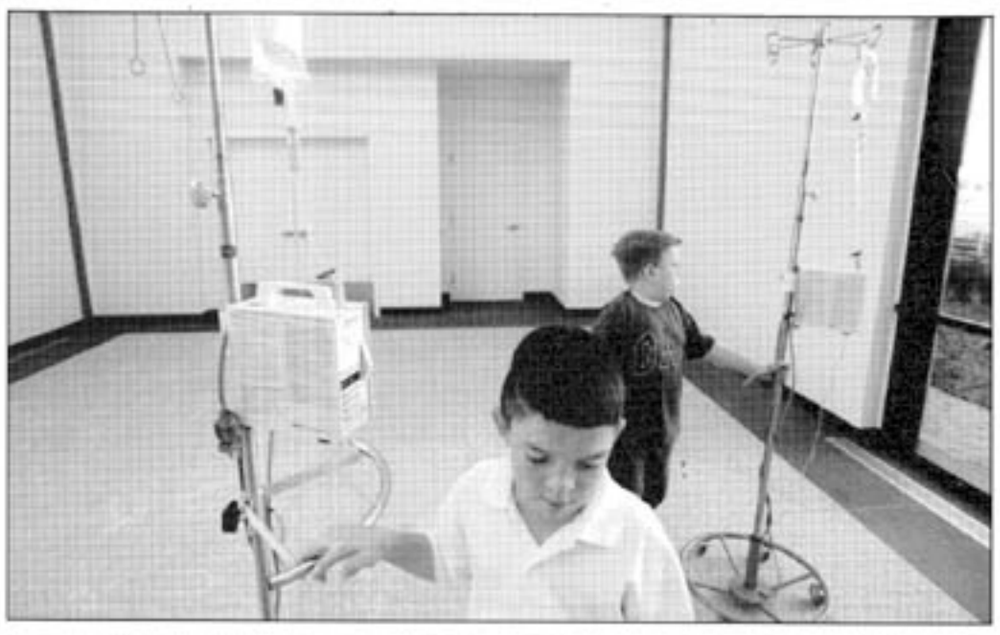
Ryan's improved condition has helped him keep and build friendships at Mary Immaculate Catholic School in Farmers Branch. Said Colin Bernier, who has known Ryan since the third grade: "We don't look at his hands. We just look at him."

With the treatments, Ryan can expect to live several decades, Dr. Kakkis said.

Life has again become enjoyable for a freckle-faced boy who no longer asks about death, Lt. Dant said.

"When I lay down with him now at night, he talks about baseball uniforms."

Tax-deductible contributions can be made to the Ryan Foundation, 3917 Alto Ave., Carrollton, TX, 75007. For more information, visit the foundation's Web site at www.ryanfoundation.org.



Ryan Dant, 11, (foreground) and Spencer Holland, 9, receive intravenous solution at UT Southwestern. Ten children nationwide with Hurler-Scheie syndrome are participating in a clinical trial for a treatment that awaits federal approval.

Jordan King, an eighth-grader at Mary Immaculate Catholic School in Farmers Branch, surprises Ryan Dant on the playground. Ryan is a fifth-grader at the school.

Ryan Dant has resumed baseball practice, coached by his father, Mark. "I want to do a lot of stuff," Ryan says. "I want to be a veterinarian — or a baseball player."

Photography by Allison V. Smith
The Dallas Morning News

Children seeking treatment face hurdles of time, cost

Enzyme-replacement therapy awaiting approval from FDA

By Tony Hartzel
Staff Writer of The Dallas Morning News

The promising enzyme-replacement therapy that Ryan Dant is receiving probably won't be on the market until 2002.

And when it's finally available to other children who suffer from his debilitating illness, it probably will cost upward of $100,000 a year to pay back an estimated $6 million in research costs. That's in addition to the $1 million contribution from the nonprofit Ryan Foundation that led to the therapy's breakthrough.

Ryan's case spotlights the often lengthy and costly approval process regulated by the U.S. Food and Drug Administration, which recently ordered a second clinical study, probably delaying the enzyme's approval until late 2001 or 2002.

"While they are looking for the perfect experiment, we are looking at kids who get worse irreversibly," said Dr. Elizabeth Neufeld, chairwoman of the genetics department at the University of California at Los Angeles. She has studied Ryan's disease, Hurler-Scheie syndrome, for 30 years.

"The FDA has been caught between the need for caution and the need for action."

That dilemma has prompted government officials to ask Ryan's father, Carrollton police Lt. Mark Dant, to speak Tuesday to FDA and congressional leaders in Washington, D.C.

The latest trial requires half of 42 new patients to get a placebo.

"I have wrestled with that, and I'm not happy with it," said Dr. Emil Kakkis, who helped develop the new treatment while at UCLA. He is conducting the clinical trials for BioMarin Pharmaceutical Inc., where he is president of the genetics division. "To convince the FDA that the changes we see are not placebos, we have to do this."

Children in the study receive the treatment to replace an enzyme that their bodies cannot make. Hurler-Scheie syndrome, or mucopolysaccharidosis, affects one of every 100,000 children. Those with the disease almost always die by age 10.

Ryan, who's almost 12, continues to get the experimental treatment each week for free as part of the original FDA study. BioMarin, which has partnered with Genzyme Corp., a medical-products company, has exclusive rights to make the drug for the next seven years so it can recoup its $6 million research tab. The companies' development costs must be borne by a relatively small number of children who have the disease.

"The FDA has to come to terms with the fact that for people with life-threatening illnesses like this, the bar for research must be improved," Dr. Kakkis said. "Then costs could come down, which could allow other drugs to be made."

The Dants expect to have four years of health insurance coverage after the drug meets FDA standards.

"There is no decision," Lt. Dant said of paying the ongoing cost after insurance ends. "We will do it — and we will do it without having everything else."

Dallas Morning News file photo

Ryan Dant, shown at age 4 with his father, Mark, will be 12 in April.