



# The **MARY FISHER** CARE Fund Clinical AIDS Research and Education

December 2006



*On a July 2006 trip to Rwanda, Mary Fisher meets with women and children.*

From Mary Fisher

## **As a fruitful year ends, some thoughts on what sustains us and what awaits us**

Dear Friends,

What a remarkable year! I spent more of 2006 in Africa than I'd anticipated. When, in May, I was named a UN Special Representative, it merely confirmed what I had already believed: That my urge to embrace the AIDS community outside the United States was more than a feeling — it was a calling, one I've gratefully accepted.

Inside this issue we've tried to describe some of our efforts in Zambia where we're working with others to promote economic development — using work, trade and marketing, rather than dependency-building aid, to bring both income and pride to AIDS-stricken families. In Lusaka, we're preparing to build a healthcare campus. When we first vis-

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## **Mary Fisher named UN Special Representative on HIV/AIDS**

Though Mary Fisher has long used her voice and art to advocate for those who share her HIV-positive status, she now does so with United Nations backing: On May 18, 2006, UN Under Secretary-General Dr. Peter Piot named her a Special Representative of the Joint United Nations Programme for HIV/AIDS (UNAIDS).

UNAIDS coordinates the efforts and resources of 10 UN organizations, including UNICEF and the World Bank. As a UNAIDS global ambassador, Mary will focus on HIV/AIDS prevention, treatment, care and support, with an emphasis on women, children and the oppressed.

"For more than a decade and a half, Mary has been an eloquent voice for compassion and for action," Dr. Piot said in announcing the appointment. "I am confident that the warmth, talent and presence she brings will help UNAIDS send a powerful message that can open hearts, minds and doors of opportunity throughout the world."

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*Mary Fisher with United Nations Under Secretary-General Dr. Peter Piot, who in May appointed her a UNAIDS Special Representative.*

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## A letter from Mary Fisher

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ited the Centre for Infectious Disease Research in Zambia (CIDRZ) several years ago, it was a fledgling promise of hope and healing. This past August, at an international AIDS conference in Toronto, CIDRZ was heralded as the model for service in developing nations – making headlines in *The New York Times* and elsewhere.

While we're gaining in Africa, I feel as though we're sliding backward in the United States. The epidemic here has settled meanly and quietly into communities of poverty, of immigrants, of powerless families and people living on the margins. CARE Fund director Dr. Michael Saag somewhat reluctantly led the national healthcare community's effort to speak to policy makers this year (see the story on page 3). We are proud of his leadership. But in an era of deeply partisan politics, Iraq gets the attention and resources while those with AIDS get added to treatment waiting lists.

Many of you who read this newsletter have supported our work for years. If you're able to travel and contribute, we'll invite you to join us on specially arranged trips I'll host in Africa during 2007. We hope your family will join ours, experiencing the richness of Africa (on safari and with dignitaries) and the reality of AIDS (in clinics and villages).

As your family prepares for the holidays,



*Mary Fisher and a new friend, Rwanda, July 2006*

please remember those for whom there are no holidays from illness. Join us as we go where the need takes us, from the First Ladies of Africa to the forgotten in Alabama. Your generous gifts are critical: Every dime given to CARE yields the kind of outcomes we saw this past year.

Please add your support in every way you can, and accept my deepest thanks.

**MARY FISHER**

## UN emissary post for Mary Fisher

*Continued from page 1*

As a special representative, Mary joins a diverse group of international notables who travel the globe on behalf of UN agencies. Other UNAIDS special representatives include musician Maestro Mstislav Rostropovich, actress Naomi Watts and Her Royal Highness The Crown Princess Mette-Marit of Norway.

Accepting the honor, Mary noted that "UNAIDS has worked tirelessly to help every pilgrim on the road to AIDS — and we with AIDS, around the world, are in its debt." However, she added, "There is so much more to do —

and thanks to medical miracles, there is so much more we can do, to prevent babies and young people from becoming HIV infected and to give HIV-positive people healthier, longer lives. As a UNAIDS Special Representative, I dedicate myself to the disenfranchised, especially women and girls — and I call on the interna-



*UNAIDS emissaries Mary Fisher (right) and Naomi Watts (second from left) visit with Zambian girls and women during a May 2006 fact-finding trip.*

tional community to join us in ensuring that they are protected and empowered."

## CARE Fund blends HIV/AIDS research with advocacy

*Dr. Michael Saag shares insights on Capitol Hill, NPR; wins federal grant for AIDS data network*

After learning she was HIV-positive in 1991, Mary Fisher spent much of the 1990s on a high-profile campaign of AIDS activism. By 2000, she concluded that public advocacy alone couldn't change enough American minds and policies. To do that, she reasoned, "We need to make a difference in research and education."

So in spring 2000, she created the Mary Fisher Clinical AIDS Research and Education (CARE) Fund at the University of Alabama at Birmingham (UAB). The Fund's founding director was Dr. Michael Saag, a leading AIDS physician and researcher. Its founding principle was straightforward: "By blending research with advocacy, we will press for a greater difference in policy, in treatment and in care."

In 2006, Dr. Saag's pursuit of that principle led him from the offices of the U.S. Capitol to the airwaves of NPR, from the National Institutes of Health (NIH) to *The New York Times*.

In April, as Congress debated reauthorizing the Ryan White CARE Act that funds HIV/AIDS patient care, Dr. Saag visited key House and Senate players in the debate. He shared a his recent study of HIV/AIDS care costs and its encouraging key finding: That the expensive drug regimen known as highly active antiretroviral therapy (HAART) was actually cost-effective, because it kept HIV/AIDS patients healthier and their overall health care costs dramatically lower.

But Dr. Saag told policymakers the study also documented "a potential crisis": Physicians and clinics treating HIV/AIDS patients consistently are reimbursed for far less than they spend on care. Private clinics that can't cover such shortfalls are closing their doors; institutions such as UAB are so far shouldering the costs, hundreds of thousands of dollars annually. If the situation persists, Dr. Saag



believes, it will leave patients without access to care and will drive doctors away from practicing AIDS medicine.

Dr. Saag repeated his concern in an interview aired on NPR's *All Things Considered*. In the early years of the AIDS crisis, "a lot of our staff burned out — they just couldn't take dealing with the patients dying every day," he told host Michele Norris. Now, "our staff is burning out again but for a totally different reason, and it's mainly from workload. Patients are living longer, so our census continues to grow — that's a good thing — but our funding is flat, so we (can't hire) additional staff."

As he seeks policy solutions for the challenges in his clinical work, Dr. Saag draws praise and support for his research work. In October, NIH made a \$2.45 million grant to a project Dr. Saag heads: creation of an electronic network to pool treatment data from 15,000 patients at seven AIDS research centers nationwide.

To decide the best treatment for patients with HIV, doctors previously relied on clinical trials conducted on relatively few patients for a relatively short time. The new data system will provide essentially clinical-trial-quality data on every patient in care, compiled long-term and available in real time, says Dr. Saag. And computers will be able to use the system's data to calculate which treatments have the greatest likelihood of success,

**Michael Saag, MD, has built his professional life on the premise that medical science, clinical care and public policy can — and should — enrich each other. While still in medical training, he conceived the plan for an HIV outpatient clinic that would do scientific research as well as patient care. He founded such a facility at UAB in 1988 and remains its director, as well as director of UAB's Center for AIDS Research. He is on the NIH Office of AIDS Research Council, the Board of Directors of the Infectious Disease Society of America, and the International AIDS Society USA. He has published more than 200 peer-reviewed journal articles, has contributed more than 50 chapters to medical textbooks, and is senior editor of the journal *AIDS Research and Human Retroviruses*.**

based on what worked for other patients.

*The New York Times* predicted the data network "could be a valuable resource to researchers." Dr. Saag calls it "a new paradigm for clinical investigation — the first formal way to track HIV/AIDS treatments and outcomes on a broad, comprehensive scale in real-time." He also says he hopes it serves as a model to create similar data networks for treating other diseases.

# 'An AIDS success in Africa'

That's how *The New York Times* described gains by the Centre for Infectious Disease Research in Zambia, where CARE Fund dollars are at work

*"On the outskirts of Lusaka, I witnessed this miracle: A man with AIDS, who'd arrived at the clinic skeletal and hopeless, within weeks was triumphantly pushing his own wheelbarrow back home... Those who kissed death now embrace life, lifting wheelbarrows that had once been their hearse."*

When Mary Fisher told that story in a packed Capitol Hill chamber in spring 2006, she gave the miracle a name: the Centre for Infectious Disease Research in Zambia (CIDRZ). A non-governmental organization working in partnership with the Zambian government and the University of Alabama at Birmingham, CIDRZ



Fewer than 20% of Zambia's pregnant women know their HIV status, and fewer than 15% receive the medicines that could prevent mother-to-child HIV transmission. Each year in Zambia, an estimated 30,000 infants contract HIV during pregnancy, as they are born, or while breastfeeding; most die before their fifth birthday.

— Photos by Mary Fisher, 2006

has begun to turn the tide against AIDS in Zambia, where one in six people is HIV-positive.

CIDRZ was conceived by a handful of Zambian and U.S. physicians who met at the University of Alabama at Birmingham (UAB). To overtake AIDS in Zambia, they believed, research and treatment would have to move as quickly as the virus itself.

That meant designing CIDRZ with its research staff alongside its care staff: Clinicians would develop new concepts for treatments, researchers would study their effectiveness, and newly-proven treatments could be swiftly shared with patients.

With UAB as its sponsor and the Zambian government as its partner, CIDRZ was established. Within two years, the center was internationally renowned for its work; clinical trials were underway, a laboratory was built, and CIDRZ was soon operating one of the largest programs to prevent mother-to-child HIV transmission in the developing world.

In 2003, the United States funded a new, \$15-billion President's Emergency Plan for AIDS Relief (PEPFAR). Zambia was named one of its 15 "focus countries," and CIDRZ was an early grantee. In partnership with the Zambian government, and with the support of UAB, CIDRZ has expanded to 90 clinical and research facilities around Lusaka.

To ransom Zambia's future, CIDRZ battles HIV/AIDS on many fronts:

- Its Prevention of Mother-to-Child Transmission (PMTCT) program has tested and served hundreds of thousands of women and their infants. CIDRZ colleagues were invited to present their groundbreaking research on PMTCT and other topics at

## Toronto AIDS Conference spotlights CIDRZ's treatment, research advances

The Centre for Infectious Disease Research in Zambia (CIDRZ), a project long supported by the Mary Fisher CARE Fund, made an impressive showing at the XVI International AIDS Conference in Toronto, Canada, in August. CIDRZ's report on its successful scale-up of antiretroviral therapy (ART) in Lusaka was featured in a special conference issue of the *Journal of the American Medical Association*, and covered in the *New York Times* with the front-page index headline "An AIDS Success in Africa."

Between April 2004 and November 2005, the Ministry and CIDRZ set out to transform HIV/AIDS treatment — essentially, to offer

the kind of medications and monitoring services that the developed world's HIV patients receive, in the resource-limited and doctor-short setting of Lusaka. The program put more than 16,000 patients on ART within 18 months, used a medical records database to track outcomes, and found that among patients on medications 90 days or more, death rates were reduced to comparable levels as in the developed world.

CIDRZ colleagues also made presentations in Toronto on the pediatric use of ART, nutrition's role in arresting HIV disease, and HIV/AIDS's relationship to cervical cancer, the #1 cancer killer of women in the developing world.



**At Lusaka's Kanyama Clinic, where CIDRZ serves HIV/AIDS patients, some children arrive with younger siblings in tow. AIDS has orphaned hundreds of thousands in Zambia, a greater share of the population than almost anywhere else in Africa. In this "deluge of orphans," one out of four family units in Zambia is now headed by an orphan under age 10, says Stephen Lewis, UN Special Envoy on HIV/AIDS in Africa.**

the 2006 International AIDS Conference in Toronto (see story, page 4).

- Its antiretroviral therapy (ART) program has enrolled 53,000 children and adults into long-term HIV/AIDS care, treating 33,000 in its first 24 months. A Centers for Disease Control official called CIDRZ's ART program "number one" among those PEPFAR funds.

- Its pediatric program has enrolled children in ART, and studied the use of ART with children, on a scale unprecedented in the developing world. It provides medications and monitoring services free for children, and is exploring ways to make facilities and procedures more child-friendly.

- CIDRZ researchers conduct ongoing research and clinical trials in critical areas where HIV/AIDS intersects with other perils to Zambian children's health, including malnutrition and tuberculosis.

Since CIDRZ's ART program launched, Lusaka's overall mortality

rate has declined by more than half. And by the end of 2006, CIDRZ expects to have nearly 80,000 enrolled in long-term HIV/AIDS care and 50,000 on ART — a pace and effectiveness unrivaled anywhere.

As CIDRZ has grown to meet the community's needs, it has outgrown its facilities. Critical functions are spread over four separate buildings, none adequate to their task. Staff leaders are removed from those with whom they must work. Such inefficiencies carry steep costs.

Mary Fisher has long supported CIDRZ through the CARE Fund. In spring 2006, she volunteered to head a capacity-building campaign called ZAMBIA FIRST. Its goal: to create a single base of operations from which CIDRZ can pursue its essential research, expand its life-saving treatment — and extend the benefits of both throughout Zambia and sub-Saharan Africa.

CIDRZ plans to build on land in Lu-

saka between the University of Zambia, a historic partner, and Kalingalinga, a high-density neighborhood with a high burden of HIV disease. The blueprint will conform to CIDRZ founders' philosophy of locating research and service delivery close to each other for easy collaboration.

In the next two years, ZAMBIA FIRST aims to raise US\$10,000,000. Of this amount, US\$600,000 already has been pledged; development will begin when US\$2,500,000 has been pledged. There is no time to waste, CIDRZ's leaders say: According to some projections, by 2014 the ranks of AIDS orphans in Zambia could reach 1 million. Speaking to journalists at the International AIDS Conference, Mary Fisher distilled the urgent needs of all Zambia's children into a single tableau: a mother and a child.

"On a low porch near an open fire over which thin stew is simmering, sits a tiny woman, shivering in the heat as she wastes away. Her mother has given up all hope for her. Her husband is angry at her wasting; he beats her. She pulls her newborn child close to her emaciated breast which gives a moment of comfort but no food. I know this woman. I have held her in my arms. I've cradled her infant son, knowing his short future. And I had nothing to offer that would save either of them."

CIDRZ offers hope for Zambia — hope of turning the tide against HIV/AIDS.

For more: [www.zambiafirst.org](http://www.zambiafirst.org).

**In the fight against AIDS, says CIDRZ's Dr. Jeffrey Stringer, "We often measure things in numbers: '33,000 people on antiretroviral drugs.' But numbers never tell the real story because it isn't one story of 33,000 people. It's 33,000 different stories — individual stories, remarkable stories of mothers able to care for children, fathers able to work, infants able to live and grow."**



# Grief, stigma — but also hope and 'tears of joy'

## Mary Fisher's journal captures the global AIDS crisis

Mary Fisher spent much of 2006 on the road, traveling the world on fact-finding and advocacy missions. On every trip, she packed her journals, to capture and express her experiences and emotions. Below, excerpts from some journal entries.

### Egypt

Cairo, January 19: "It seems early in the epidemic here," Mary writes. Some basic HIV/AIDS medications are free — but not the more-effective second-line drugs that are widely used in the developed world. "The stigma and unwillingness to talk about sex is keeping the majority of infections" from being reported, she believes. When she meets with members of an HIV-positive support group, they speak only anonymously, fearfully; they ask her not to photograph them or record their names.

"I met with a woman, 'C,' who has two children; her husband died and now his family wants to take her apartment and belongings, trying to say their son's HIV was her fault. Her children are scared ... her own siblings have walked away from her ... her sister's husband won't let C visit them and her sister won't fight. They actually moved away, C doesn't even know where her sister has moved... While C was speaking, (another HIV-positive woman) began to cry, saying she too was afraid this was going to happen to her... They are all afraid, don't want anyone to know."

### Rwanda

Kigali, July 18: "Empowerment of women extremely important," says one of Mary's first entries here — a theme she sounds repeatedly in meetings with African officials. Here as in Zambia, an average citizen lives on about US\$1 a day, and women have even fewer opportunities than men for paid work that would bring social status as well as income.

Rwanda is still recovering from the 1994 genocide in which more than 800,000 perished. But today, Rwandan women — Hutu and Tutsi, HIV-



Mary Fisher joins Rwandan women learning how to weave traditional baskets that can be sold abroad to generate income for the women and their families.



positive and uninfected — sit together and weave native baskets for sale abroad, in income-generation projects sponsored by First Lady Jeannette Kagame and Mary's friend Willa Shalit, a U.S. businesswoman. Armed with what she learns from these projects, Mary aims to create similar ones for HIV-positive women in Zambia.

"First stop: Madame Kagame's HIV+ women basket weavers. There was training taking place and we were shown the baskets and how they are trained and how they are given meds; medical services are free to these women. I sat to learn how to weave ... I spoke to the women about my status and their lives and mine. We hugged and laughed and danced as

they showed me their baskets. Willa told them the baskets were so beautiful (and they were) that tomorrow she would come back and buy all of them and would continue to buy from them as they can make them. They were overjoyed ... This income generation project works so well..."

Mary next visits Madame Kagame, who pledges support for Mary's efforts in Zambia. "We spoke of how important income-generating projects are in this country especially because of the genocide. There are many stories of success here ... about the men staying home to sit with the children and the women going to train and bringing home the money — and so abuse is turning around, men are treating women as if they are queens of the house. It is amazing and wonderful and brings incredible tears of joy."

July 22: Mary's final entry of the trip notes that women she met "gave me my Rwandan name: Nyirarakundo. It means 'she who has great love,' and they say I have given so much away and have an abundance of it."

### Zambia

Lusaka, Oct. 19: Mary has seen how even modest earnings can change the lives of HIV-positive women: "They can pay their children's school fees, buy food for their families and food they need to take their medications." So on her third trip to Zambia this year, she focuses on key business issues: What products to make, with what raw materials, in what work settings? Over six days, she calls on agencies and officials that might help, from the U.S. Embassy to the African Development Foundation.

Oct. 20: Dr. Mark Dybul, the U.S. Global AIDS Coordinator, is touring HIV/AIDS facilities. Mary accompanies him to the Kanyama Clinic where the Centre for Infectious Disease Research in Zambia (CIDRZ) provides treatment and care. "The clinic was incredible ... I think it was very evident the amazing work that CIDRZ

*Continued on next page*



Whoopi Goldberg and Katie Couric emceed the Oct. 16 WWO gala honoring Mary Fisher. — UNAIDS / W. Lee

## Worldwide Orphans Foundation honors Mary Fisher at gala

At its second annual gala Oct. 16 in New York City, the Worldwide Orphans Foundation (WWO) gave its top honor to Mary Fisher and raised \$1.2 million for its mission: Providing medical, developmental and other aid to

orphans worldwide. After the honoree spoke (see page 8), the standing-room-only crowd was serenaded by four Tony Award winners, and by five HIV-positive orphans from Ethiopia whose lives WWO has transformed.



## UN acquires Fisher art

"Courage" (above) is one of seven sculptures by Mary Fisher that were installed in November in the permanent collection of the Joint United Nations Programme on HIV/AIDS (UNAIDS) in Geneva, Switzerland.

## Mary's Journal

*Continued from previous page*

does: Kanyama Clinic serves 200,000 people... there are 6,000 births there a year ... staggering numbers. Mark met with families that have been helped by antiretroviral drugs, and then met with peer educators and asked questions. It was very powerful...."

*Accompanied by CIDRZ officials, Mary goes to Zambia's State House to meet with an old friend, First Lady Maureen Mwanawasa. "Maureen was wonderful as usual. I told her about the (income generation) project in Rwanda ... She said she would make sure that she helped us to make it happen in Zambia ... do whatever it takes from their point of view to further this project...Zambia is your country, Mary," she said ... It was a really great meeting."*

*At a community clinic, Mary and her assistant Penny Morgan meet with HIV/AIDS support group members to experiment with beading, crocheting, weaving and other crafts that might yield income-generating products. "It was quite a scene to watch me teaching them how to do bead crochet. Penny and I gave out the supplies; there were more women than supplies and they were incredibly eager. Some caught on quickly, others got frustrated ... We need to spend days*

doing this, not hours.... They can do this and want to ... We sat outside under the trees on benches trying to answer a million questions.

*"Penny pulled the loom out and showed them how to warp it ... One woman took such a liking to the weaving we left her with the loom and some supplies. Other women took some of the raffia and started braiding it to make a mat...We'll see. We took down everyone's name and what they took with them. It was fast and furious and left me feeling that we had a lot more prep we could do to make it work, but the willingness and excitement was palpable...."*

*Oct. 21-24: Mary travels through Zambia, meeting with HIV/AIDS support groups and visiting women artisans. In Mongu, she meets women who weave traditional baskets in their homes. Back in Lusaka, she learns of a program where AIDS widows and orphans crochet colorful bags and donate half their earnings to support a local teacher and community center. On one of this trip's last journal pages, she writes:*

*"It is amazing, the amount of goodness and love that is being poured into this country... It's really hard for me to leave Lusaka and all these incredible people. I'm energized, however, by the prospect of bringing income generating projects here. I believe we can do it."*

# 'This Little Light' shines on true family values

Excerpts from "This Little Light of Mine," Mary Fisher's speech Oct. 16 to the Worldwide Orphans Foundation gala.

America has heard much about "family values" in the past few decades. It's a phrase that's been hijacked by some who believe only they can define a family and only their values matter.

My parents refused to join them because they believed family values had to do not with judging others but with serving them ... The underlying lesson each of my parents taught (eventually) to their five children was that with privilege comes responsibility. Giving back to the community that surrounds us or the world that supports us is not nice; it's necessary....

We live, you and I, in a world divided between the privileged and the oppressed, white and black, Israeli and Arab, Muslim and Christian.... It's a world of us against them, of branding as "evil" those who distrust us, of cowering in social bunkers with those most like us, hunkering down during shaky times. And out of this chaos we have perfected the art of creating orphans.

From Rwanda to Russia, Ecuador to Ethiopia, we have killed and raped and brutalized each other until we are surrounded by orphans. We have stacked them in warehouses, spread

them across the dusty fields of Africa, and tried our best – at a safe distance – to think happier thoughts. We want to distance ourselves from them, as a nation, as a society, because we do not want to contemplate their suffering. Children are the primary casualties of our wars and our selfishness. Orphans don't just happen; we – adults, policy makers, ordinary Americans voting ordinary America self-interests – we make them. But we do not want to be responsible for them. To all of this, my parents' values would say, in McAuliffe's famed words at the Battle of the Bulge: "Nuts." ...

In addition to my parents, AIDS has been a teacher in my life. For the first five years after my diagnosis, before any life-sustaining drugs were available, I was dying. My ex-husband Brian died during those years, leaving our two children with one parent also headed for the grave. I did not die, but I spent five years dying before the miracle of new medicines. And dying taught me that the length of life is not as important as its depth...

In recent years, Africa has been the classroom richest in lessons and memories, in laughter and in tears. If you want another cause to support, see me afterward. I'm leading a campaign to raise enough money to fund

a healthcare campus in Zambia where one out of every four families is now headed by an orphan no more than 10 years old, caring for younger orphan-siblings.

Do you know what these little orphan bands are? They're families, woven together so tightly by love that the oldest child will not let the littlest out of her sight; where the oldest brother will carry the youngest, give up his food for the hungriest, and gently bury his little sister when she dies...

Clearly, here, those who are privileged have obligations. Here, the values are unspeakably plain. The issue is settled when you watch the orphan families scrounge a living from the dust. Here you will understand the meaning of "family values" in ways so rich it is an embarrassment...

In the darkest corner of the darkest orphanage, a tiny light comes on. It's your light – your dollar, your commitment, your gift of life and love in a place so barren of both. When you see one tiny light turned into thousands, when our lights become "theirs," something else will happen. Over the sound of an orphan's cry will come the voice of an ancient rabbi, speaking to you who have become a light giver: "Grace to you, and peace."

## A gift from Mary, to thank you

Your generous support makes our work possible. As thanks for your gift of \$75 or more, The Mary Fisher CARE Fund will send you *One Woman's Voice*, a collection of excerpts from speeches Mary Fisher has given since 1995.



## I'd like to help The Mary Fisher CARE Fund continue its important work.

Enclosed is my tax-deductible donation:

\$ 25 \_\_\_\_\_ \$ 50 \_\_\_\_\_

Donors of \$75 or more will receive the Mary Fisher speech booklet, *One Woman's Voice*.

\$ 75 \_\_\_\_\_ \$100 \_\_\_\_\_

\$200 \_\_\_\_\_ Other: \_\_\_\_\_

Please make checks payable to The Mary Fisher CARE Fund.



## The Mary Fisher CARE Fund

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