



# The Michigan AIDS Fund

A COALITION OF COMPASSION FOR TWENTY YEARS

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Written, compiled and edited by Barbara J. Getz, Founding Chair and Board member

1989-2009

## PREFACE

Few people are given the "opportunity of a lifetime." Even fewer are given that opportunity twice. This project to chronicle the history of the Michigan AIDS Fund (MAF) has given me both. There are a handful of us, current and former philanthropists, who were blessed with the challenge of constructing Michigan philanthropy's response to the AIDS epidemic of the 1980s and 90s. We were passionate about the need for such a response, and we were undaunted in our zeal to achieve it. This project has permitted me to remember that original opportunity, and it has given me the chance to relive it now, twenty years later.

What we created in 1989-90, and what Michigan philanthropy has supported in so many exceptional ways, has lasted for an unprecedented twenty years under the aegis of the Council of Michigan Foundations (CMF). Over the course of those years, the epidemic and the disease evolved from an acute, fatal mystery to a chronic illness that can be controlled to a large degree by

a battery of drugs. The Michigan AIDS Fund, its character and its responses have evolved right along with it.

*"The main point was getting the job done for people who were sick, afraid and dying – not the politics of quid pro quo or do-no-harm objectivity. I think it was this open demeanor of mutual respect and compassion that made us a trusted and neutral partner in a time of marginalization and stigmatization. None of it could have happened were it not for the original conveners' determination to put aside personal agendas for the greater good."*

~ BARBARA J. GETZ, FOUNDING CHAIR  
AND FORMER BOARD MEMBER, MAF

That the Michigan AIDS Fund reflects a certain personality is clear in the responses it has evoked from those interviewed for this history. We selected the interview nature of the piece to reveal that personality. What follows are excerpts from more than two dozen conversations with people who have been deeply involved with the Michigan AIDS Fund – some from the earliest conversations in 1989, others from that first generation of the Fund's leadership and grantees, and still others reflecting later years of change and adaptation. These are the voices of committee and board members, staff, grantees, public health leaders and, of course the larger world of philanthropy, the National AIDS Fund and CMF, without whose unfailing support the Fund might have foundered any number of times.

*"In remembering all those years of work and learning,  
I have one very clear thought: it was the right thing to do."*

~ IRA STRUMWASSER, FORMER BOARD MEMBER, MAF; BLUE CROSS BLUE SHIELD OF MICHIGAN FOUNDATION

*"The late '80s were a tumultuous time with regard to HIV/AIDS. Those were amazing times, they were frightening times, and the timing of MAF coming together to support our work was extremely critical to MAPP and all of us working in that environment."*

~ CRAIG COVEY, FORMER EXECUTIVE DIRECTOR, MICHIGAN AIDS PREVENTION PROJECT (MAPP), NOW MICHIGAN AIDS COALITION

## THE CONTEXT

**1981:** CDC forms Task Force on Kaposi's Sarcoma and Opportunistic Infections (KSOI). Initially believed to be limited to the gay community, the still-unnamed disease is discovered among injecting drug users by December. First AIDS case recorded in one Michigan county. **1982:** 452 cases of cancer, pneumonia and other opportunistic infections in 23 states have been reported to the CDC. AIDS is first named by the CDC in September. **1983:**

The number of US AIDS cases rises to 3,064; 1,292 have died. **1988:**

There are an estimated 2 million AIDS cases in the US; nearly 16,400 people have died. **1989:** The death toll marches to more than 54,400, with 90,280 cases of AIDS reported by CDC. In Michigan, 1,120 cases reported, of whom 650 have died...

AIDS first appeared in this country among gay men, injecting drug users and Haitians – people without much in common with many of us. The stigma and injustice flung at these ill and dying individuals, while born of fear and uncertainty, was more than most of us could bear.

"There's a real irony here, and a personal story. One of the changes in how America looked at AIDS came from a 13-minute speech in Houston in 1992, from one of the MAF's board members and a very close personal friend. That's a piece that's forgotten: that Mary Fisher was with

MAF when she gave the Republican National Convention speech that is now rated as one of the most significant 100 speeches given by an American during the 20th Century. This probably says less about the speech than about the time – a time when beautiful young mothers didn't have AIDS."

~ A. James Heynen, former director, MAF; founder, Greystone Global

*"I really think, particularly in the decade of the '90s, MAF was the right organization in the right place at right time. It enabled AIDS Partnership Michigan to grow incrementally to become the organization we are today. You have been an enormously fine partner."*



~ BARBARA MURRAY,  
EXECUTIVE DIRECTOR,  
AIDS PARTNERSHIP MICHIGAN

"What sticks out in my mind is the strong sense of collaborative effort and the fact that we were trying to address a multitude of issues related to HIV/AIDS for individuals, families, and communities. It wasn't just about the disease; it was about compassion, and the fragileness of life."

~ Dr. Carolee Dodge Francis, former board member, MAF; Oneida Nation of Wisconsin

"My first impression of the founding board of MAF was that they were passionate, and more than passionate, they were compassionate, as well.

That board knew that this affected all of us, not just someone out there, in terms of lives lost. What got my attention was when I realized that AIDS accounts for so many more years of lives lost than any other thing in Michigan. This really hit home when I first saw the AIDS Quilt."

~ Earl Schipper, former executive director, MAF

*"MAF has been an exemplar of what I see funders, agencies, leaders and staff doing together to fight the infection and to help those affected live with dignity – they do whatever it takes... they put those they serve first."*

~ CHRISTINE AMEEN, FORMER ACTING DIRECTOR, MAF

## EMERGENCE AND COLLABORATION

In a rare coalescence of timing, energy and inspiration, three entities felt the urgent need for a private philanthropic response to AIDS in Michigan in the late 1980s. The State of Michigan's then Department of Public Health knew that the money available for this mushrooming threat was not nearly enough to meet the estimated costs of intervention. The Council of Michigan Foundations' CEO Dorothy Johnson and her colleague, Bill White, CEO of the C.S. Mott Foundation were anxious to see the state's foundations step up, and a handful of foundation staff members began discussing among themselves the need to do something. The three elements of demand came together and, with a monetary challenge in hand from the C.S. Mott Foundation, the founders began to hammer out the shape of a response – a groundbreaking funding collaborative unlike anything tried in Michigan before.

With such stigma and the overwhelming scope attached to AIDS, it was agreed that no one foundation could take on the disease, but together several of us could and should... and did. We formed a collaboration of funders, but more than that. We forged collaborations with our grantees, fledgling and fragile organizations born of need and the high emotions attached to the deadly disease. We collaborated with public health departments at the

city and state levels where funding was not high but experience and knowledge were great. We maintained collaboration with the National AIDS Fund where we were tied in to the national scene and progress of the epidemic.

"I would say MAF was a front-end godsend. The willingness of Michigan philanthropy to dive in where public policy refused to go was essential. We should have been one of the highest states in numbers of AIDS, given our numbers of needle users and the size of our gay community. We were successful in changing that prognosis because things were done when no one else would do them."

~ Jean Chabut, deputy director, Michigan Department of Community Health

"So many grantees have a certain stereotype in mind when they think about foundation folks. MAF wasn't like that. The Michigan AIDS Fund was approachable, innovative. I've always seen MAF as an entity that

saw a need, planted a seed to get something started, and took on the issues that couldn't be taken on by the public sector. I've always had the utmost respect for the Michigan AIDS Fund."

~ Brooke Borgeson Gray, RN, MSN, FNP, formerly Wellness Networks Grand Traverse Area; Traverse Health Clinic

*"MAF has proven that collaborative grantmaking can be extraordinarily successful for the community, and unexpectedly rewarding for the individual philanthropists who are involved, especially when those individuals are human beings who happen to be in the world of philanthropy. Complex human issues can be solved when you bring heads and hearts together."*

~ GLENN KOSSICK, FORMER BOARD MEMBER  
AND CHAIR, MAF; TRUSTEE,  
METRO HEALTH FOUNDATION

*"I come away from my time with MAF, first as chair of the committee that dealt with the project on behalf of CMF, then as a member of the Fund's board and finally as board chair, with a genuinely good feeling about the board and about the work of the Fund. We all participated over and above the typical board; we were more like a family. And we did good things in an area where not many good things were happening."*

~ LEONARD SMITH, FORMER BOARD MEMBER AND CHAIR, MAF; FLINN FAMILY FOUNDATION

## IMPACT

That the Michigan AIDS Fund had an impact on the progress of the epidemic in this state is undeniable. With evolving priorities in care, capacity-building for grantee organizations, peer education for teen prevention and harm reduction, MAF identified gaps and tried to fill them. At first, it was the creation of a parallel system of care for people whom no one else would touch. We spent time listening about where and how the need could be addressed. We listened to public health officials and we listened to grantees. The Fund convened several annual conferences on AIDS for grantees, funders and public policy makers. It was important to link the programs across this vast state with each other and with the Fund for networking, mutual support and knowledge exchange. As the disease became more manageable, the Fund identified prevention as a priority, and, within that priority the politically charged area of syringe exchange, for which the Fund is known world wide.

It was in the arena of syringe exchange, that the Fund got its feet most wet in public policy work, convincing the City of Detroit to approve a model program that later was translated to other cities in the state. The tension between funding programs and funding policy advocacy has always existed, and it remains an area of active discussion today.

One of the most telling areas of impact, however, was on the early leaders of the Fund.

We came to the table to try to change things, and we found ourselves changed. Representing mostly traditional foundations, board members became involved in the very hands-on grantmaking required by the

grass-roots organizations that needed our support in more ways than monetarily. Those of us associated with the Michigan AIDS Fund over the years have each taken something away in greater measure than we might have contributed. Importantly, we each learned what we, as grantmakers and as individuals of conscience, can *not* be.

"It's not what Kellogg did for HIV/AIDS that mattered in this collaborative, it's what MAF did for Kellogg that was the real surprise. We learned so much more about the interconnections between health and the array of educational, social, and policy issues than we'd ever dreamed of when we started, and it underscored a broadening interest in working collaboratively that we'd not fully appreciated before."

~ Thomas Bruce, former board member, MAF, and former program director, W.K. Kellogg Foundation; University of Arkansas for Medical Sciences

*"The Fund was visionary in being able to do things that the public funders or agencies would not be able to do on their own. It was brave enough to initiate certain conversations that many times were controversial. MAF was able to do that; it was needed. Even though things are a lot different than they were, I think that we would be in a much worse situation if we had not had an AIDS fund stirring up some of those conversations, particularly around syringe exchange."*

~ LORETTA DAVIS, FORMER BOARD MEMBER,  
MAF; HEALTH DIRECTOR,  
WAYNE COUNTY HEALTH DEPARTMENT

"The willingness of MAF to come together, organize and actually deliver funding at the local level was absolutely a miracle in Michigan and set a standard for the rest of the country. It happened at a time that was critical: 1990 to 1998 was a time when the guts of intervention and prevention standards were being developed and tested to see what worked. Everything now is based on science and results; the bottom line is that the Michigan AIDS Fund helped define what we were looking for in terms prevention

program outcomes."

~ Randall S. Pope, former director HIV/AIDS prevention and intervention service, Michigan Department of Community Health

## LESSONS

It was hard to learn that foundation staff members are not at all good at raising money from the broader public. We had success within our own organizations and amazing success at that. Spurred by the novelty and safety of the collaborative funding model, foundations that would not normally fund a single disease or issue came willingly to the table and stayed far beyond a normal time-span. Among less well-known funders, however, we were not adept at asking for money, and it is one area where we would need to alter our approach in the future.

All organizations are alive within the environments that surround them, and must grow and adapt in order to survive. The Michigan AIDS Fund is no exception. The Fund has been blessed with leadership, staff and board, who recognized the benefit of change when change was needed and who were never afraid to explore all the options open to us, whether it was in structure or funding priorities or the actual adoption of programs. Flexibility has been a hallmark, and one that has stood the test of remarkable change: in the disease and in the non-profit, public and grantmaking sectors' responses to it.

"MAF in a nutshell: People doing good things for an extremely serious need. There was great inspiration observing you all doing good things that I knew would make a lasting contribution and a model not only for other funds all over the country, but for other things that need to be accomplished. And you good people working towards a good end became very much like a family in your affection for one another. You must feel satisfied about where this is now, at a natural stage of its life with

permanence ensured. I hope the MAF goes down in grantmaking history as a model to be used by others."

~ Dorothy A. Johnson, former president, Council of Michigan Foundations

"For the first 20 years of its existence, the accomplishments of MAF have been astounding. Is there more work to be done? Absolutely. Clearly the mission crafted by the founding board members was vitally important, and it was durable."

~ Elizabeth Sullivan, former board member and chair, MAF; vice president, Community Foundation for Southeastern Michigan

"We were always the model neutral convener and the one entity everybody trusted. I know it doesn't have anything to do with money or funding, but I cannot tell you for how many agencies going back all

these years that single thing, above anything else, was our hallmark. Through our conferences, through our even-handedness, through our ability to bring different people to the table to talk about the issue, we could get different people to sit down and talk with us when they wouldn't talk to each other. That, more than anything else, enabled us to do all the other things we did."

~ Terry Ryan, staff member; Michigan AIDS Coalition

"From both perspectives, AIDS and Hepatitis C, we can't just sit around and wait for the ban (on syringe exchange) to be lifted. We need to make sure needle exchange programs are funded and functioning for everyone's benefit. It's not over."

~ Harry L. Simpson, executive director, Point of Change

*"We asked tough questions that organizations rarely ask themselves, which allowed us to refocus our mission, and everyone agreed our work was not over. You can't be all things to all people. You have to know your niche and focus on what you were good at. We saw our niche as HIV prevention, so as a model we narrowed our focus and our mission to reflect that."*



~ STACEY BARBAS, FORMER EXECUTIVE DIRECTOR; PROGRAM OFFICER, THE KRESGE FOUNDATION

*"MAF has been on the cutting edge of strategic grantmaking and leadership development. They use our Challenge Grant resources to support syringe exchange programs – a critical gap in current funding. And for years they have consistently fielded the most diverse AmeriCorps team."*

~ KANDY FERREE, PRESIDENT, NATIONAL AIDS FUND

## TRANSITION

MAF's mission "to support efforts to prevent the spread of AIDS and to alleviate the suffering of those infected and affected by HIV/AIDS" continues through the Michigan AIDS Coalition, newly formed from the merger of MAF and Midwest AIDS Prevention Project. As such, it rests within a structure that embraces all three of today's goals: prevention of HIV transmission, public policy advocacy on behalf of persons living with the disease, and continued grantmaking to targeted programs and projects.

All of those interviewed for this project agree: it is not over. Transmission of the virus remains a strong concern, especially in communities of color, in young people untouched by the disease's early, acutely fatal nature, and in populations of injecting drug users. Diligence in prevention activities and in promotion of policies that both support prevention efforts and incorporate responses to this now-chronic illness as benefit other chronic illnesses is necessary and must not flag because

AIDS is no longer a headline issue. The facts remain: since the first reporting in 1981, 9,687 Michigan residents have died of HIV/AIDS related causes; today there are more than 14,000 people in Michigan living with HIV disease, including AIDS.

IN THE 20 YEARS SINCE ITS INCEPTION, THE MICHIGAN AIDS FUND HAS BEEN SUPPORTED BY MORE THAN 40 FOUNDATIONS AND CORPORATE GIVING PROGRAMS, AS WELL AS DOZENS OF INDIVIDUALS, AS IT TEAMED WITH THE STATE OF MICHIGAN AND THE NATIONAL AIDS FUND TO DISTRIBUTE APPROXIMATELY \$12 MILLION TO NON-PROFIT ORGANIZATIONS DEALING WITH HIV AND AIDS THROUGHOUT THE STATE.



Back in the late 1980s there were all kinds of things grantmakers could and should have taken on. We chose the darkest and ugliest of them. In forming a partnership response to AIDS, we had brilliant success – not without inevitable hitches, but brilliant nonetheless. There are other societal issues of urgency and risk that call for use of the Michigan AIDS Fund model, and for its expansion into areas we might have gone had we a crystal ball to view the future. It is our great hope that this model will be employed and adapted wherever the scope and risk call for a collective approach. Keywords to remember: mutual

respect, neutrality, flexibility, partnership – each of them important among participants, with grantees, and with the public sector.

*"CMF is very proud of the effort of Michigan's funding community in supporting the Michigan AIDS Fund as a part of the Council. It really did put a collaborative model in place that we've used a number of times since to help Michigan address tough issues."*

~ ROBERT S. COLLIER, BOARD MEMBER; PRESIDENT, COUNCIL OF MICHIGAN FOUNDATIONS

FOR MORE INFORMATION ABOUT COLLABORATIVE RESPONSES TO

HIV-AIDS IN MICHIGAN, CONTACT:

MICHIGAN AIDS COALITION

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PHONE: 248-545-1435 OR 888-A CONDOM

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INFO@MICHIGANAIDSCOALITION.ORG

MICHIGANAIDSCOALITION.ORG

*"We are still in a transition mode, and I think it will probably take another year before we consistently think of ourselves as "MAC." In the end, though, we'll be even stronger and thousands of people who had no clue about HIV transmission will know."*

*~ HELEN HICKS, EXECUTIVE DIRECTOR, MICHIGAN AIDS COALITION (MAC)*

*Read and download the full report,  
"The Michigan AIDS Fund: A Coalition of Compassion"  
at [michiganfoundations.org](http://michiganfoundations.org).*



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