HIV SPECIALIST DR. PAUL BENSON AND THE STORY OF AN EPIDEMIC

In the Beginning

Once upon a time, there was a young doctor named Paul Benson. Fresh from his residency in 1980, board-certified as a family doctor, he hung out his shingle in Berkley, Michigan, excitedly anticipating a fulfilling, and quite conventional, career as the next Marcus Welby.

But then an odd sort of patient started showing up at his office, infrequently at first and then in greater numbers. These unfortunate patients suffered from any number of rare, serious conditions—conditions that generally very soon proved fatal. Typically they were frightened, self-conscious, secretive, in some cases even ashamed about their illness and really their lifestyle. They were gay people and illegal IV drug users, people who had been pressured by society to remain in the shadows, people who came from a very different world from Marcus Welby, and now there seemed to be something terrible devastating their communities.

Back then, no one knew what virus caused this syndrome of unusual and deadly diseases: HIV had not been discovered. For that matter the term AIDS was not yet in use. When Dr. Benson first encountered these patients and investigated what might be wrong with them, he discovered that there was an apparently new syndrome spreading in certain populations that had been named GRID, for Gay-Related Immune Disorder.

The more Dr. Benson learned, the more disturbing it all was. He heard horror stories about GRID sufferers being turned away from hospitals, about doctors refusing to accept them as patients. With uncertainty about how, and how easily, this deadly syndrome was transmitted, people—including plenty of medical professionals—were running scared, reluctant to put themselves at risk.

But Dr. Benson was one of the doctors who did not turn such patients away. And so they kept coming, becoming a bigger and bigger portion of his practice, and his life.

At the time there was no such thing as an HIV-specialist—or a GRID-specialist—at least not in an official sense. But through his experience and through educating himself about the syndrome, Dr. Benson became an unofficial, self-proclaimed specialist.

In those early years, he learned as much about how to help people with their end-of-life issues as he did about treating what ailed them. A big part of his job was helping people to die with dignity, and with less pain. The most you could hope for were small victories. Perhaps with your help a patient could make it to another birthday, to Christmas.

Dr. Paul Benson. "If I were HIV-positive I'd want to come to a practice just like we have here."

Many times he'd be there for a young man throughout the dying process, and then contact the family only to find out that they had no idea their son had been dying, or had even been sick or in the hospital, and apparently no idea he'd been gay. "Those were very different, dark days."

Many HIV sufferers and their loved ones were appalled at the apparent uninterest they perceived from society toward the epidemic. There were 2,000 cases before a single newspaper article was written about it in the mainstream media (in the *Wall Street Journal*). President Ronald Reagan famously declined to even utter the word AIDS in public until 1985, after it had already killed thousands of Americans (though his press secretary had joked about it as early as 1982). The urgency, the funding to properly address the problem was frustratingly lacking.

It became a time of rage, of protest, of activism—the era of ACT UP. Some embraced conspiracy theories. It was but a short step from perceiving gross indifference to inferring instead malevolent intent: Perhaps the whole epidemic had been manufactured by the government and targeted at ostracized groups from genocidal motives.

HIV Today

Of course the situation has massively changed in the years since those "dark days."

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The single biggest leap forward in HIV treatment in the intervening years occurred in 1996 with the introduction of protease inhibitors.

Now HIV is a chronic, manageable disease. Most HIV-positive people need only take one pill per day, with no side effects.

With the Ryan White program, every American can be treated for HIV in a way that is affordable for them, including medication.

Dr. Benson cites two large cohort studies that found that there is very little difference anymore in life expectancy between an HIV-positive person who takes the proper medication as directed and a similarly-situated HIV-negative person. One study, for example, found that a 25 year old HIV-positive person had a life expectancy of 85, while a 25 year old HIV-negative person had a life expectancy just six months longer.

Dr. Benson can now tell a newly diagnosed person that HIV is no longer something to die from, but something to live with. "HIV is not going to be a problem with your life expectancy if you practice common sense."

Another big change has been funding. No longer can one say that HIV is ignored, that its sufferers are not being valued as much as those who suffer from other serious conditions, that it is last in line when government funds are handed out. The years of outrage and protest brought HIV out of the shadows, and like breast cancer which has seen similar publicity and political pressure, it has moved to the head of the line. Dr. Benson says that whatever inadequacies there may have been early, "the government has done a terrific job responding to HIV and making resources available."

The Ryan White program especially has been a godsend to many patients. This is a federal program that provides health care assistance to HIV-positive people who are uninsured. With the Ryan White program, every American can be treated for HIV in a way that is affordable for them, including medication.

Dr. Benson notes that if he has an indigent, uninsured patient with HIV, he can get them the financial assistance they need far easier than if they had been diagnosed with, say, diabetes.

There is far more money available now not only for treatment but for research.

Dr. Benson has been involved with the research side of HIV since near the beginning when he participated in numerous expanded access programs where he received drugs for his patients that were still in the experimental phase and had not yet been approved by the FDA. Participation in these programs required a heavy load of paperwork and recordkeeping, but it meant that his patients could get drugs that could potentially help them that otherwise would not be available to them.

He augmented his participation in these programs by networking with other physicians who participated in other such programs. That way, since they had access to different drugs, they could direct patients to each other to try different medications when nothing yet was working for them.

He has continued his involvement with expanded access programs off and on over the years, but soon it evolved into his also doing drug studies for pharmaceutical companies. Again the benefit for his patients was that they could get access to drugs that might help them that were not yet approved for the general patient population.

Over the years Dr. Benson has participated in almost a hundred drug studies. As the principal investigator, he has a dedicated staff including two study coordinators and a sub-investigator physician assistant.

The studies are double-blinded and involve either testing one dose against another dose, or testing an experimental drug against an established drug. In order to ensure that all his patients involved in the drug studies receive treatment, he chooses not to participate in drug studies where the control group receives placebos (though he notes that such studies have become increasingly rare anyway).

HIV is now a recognized specialty of the medical profession, with credentialing provided by the American Academy of HIV Medicine. So Dr. Benson is an official, rather than self-proclaimed, HIV specialist. He takes the board examinations every two years to maintain that status.

He is also a certified research professional, another designation that required additional training and testing.

With HIV becoming a manageable condition, much of the focus has shifted from treatment to prevention. Here too things are much, much improved from where they once were.

There is now a medication called Truvada for people who are HIV-negative but at high risk for becoming HIV-positive. It's basically the same medication used to treat HIV-positive people, but multiple studies, including the iPrEx study, have established that it is also effective in HIV prevention. Like the pills prescribed for treatment, Truvada is taken once a day.

In addition, there are promising medications in the pipeline

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that would require getting an injection every 30 or 90 days instead of having to take a pill every day. Dr. Benson expects these to be available for prevention within five years, and possibly for treatment as well.

Prevention receives heavy emphasis in Dr. Benson's practice. He offers HIV testing in his office, and counsels his patients about how to avoid HIV and other sexually transmitted diseases. He operates an HIV website—www.bewellaware.org—that focuses especially on prevention.

Transgendered people are a whopping 50 times more likely to be HIV-positive than non-transgendered people.

The Struggle Continues

Yet for all the progress in the fight against HIV, for all the good news, in multiple areas there is a great deal more work to be done.

The remaining difficulties are every bit as much social as they are medical in a narrower sense. The discrimination, the ostracism, endured by some of the populations that are especially vulnerable to HIV infection have thankfully lessened over the years, but have certainly not been eliminated.

When people engage in behavior that is illegal, socially disapproved, religiously condemned, etc., when they are pressured to feel guilty or ashamed about what they are or what they do, to keep it secret, to lie about it, this has medical consequences. With something like HIV those consequences can be devastating.

The populations at highest risk of acquiring HIV are men who have sex with men, IV drug users, sex workers, transgendered people, and incarcerated people.

Dr. Benson is especially sensitive to the plight of the transgendered. Transgendered people are a whopping 50 times more likely to be HIV-positive than non-transgendered people, so as an HIV specialist, he's had significantly more transgendered patients over the course of his career than the average family doctor. "These are people who are much misunderstood and ostracized. They often live their lives in hiding and shame." He hopes that there will be the same kind of progress for the transgendered as we've seen for gay people in recent decades. There has been a little movement in that direction in recent times—people coming out publicly as transgendered, transgendered people appearing on TV and in pop culture—but it's still at a very early stage.

Dr. Benson asks us to imagine a transgendered person who is perhaps not as convincing in their chosen gender as some. There they are in a doctor's office waiting room, drawing stares, whispers, and smirks—or certainly imagining and dreading that people are reacting that way to them—and then to make it worse when their time to see the doctor comes their name is called out as "John" (which is their name on their ID and paperwork) but they identify as "Joanna" and are dressed accordingly, and they have to make the walk of shame past the other people in the waiting room. It's no wonder that many transgendered people avoid all such contact with the health care system for as long as possible, with predictable consequences.

Actually his own attitudes and practices have changed over the years. Early in his career, if he had a transgendered patient like that, he was embarrassed for them in that kind of situation, and tried to lessen the humiliation (for instance by instructing his staff to get them in to see him as quickly as possible). Now his approach is that if there's someone in his waiting room that isn't comfortable in the presence of a transgendered person (or a person of a certain race, or an elderly person with mobility issues, or what have you), that's their problem. They can find another doctor as far as he's concerned: "I'm not going to accommodate myself to them."

He doesn't treat one patient different from another. His office welcomes everyone. "If you're nice to me, I'm nice to you."

He loves his eclectic practice, where he treats everything and everyone. Though our emphasis here is on his work as an HIV specialist, in fact only maybe 20% (roughly 1,000 out of a total of roughly 5,000) of his current patients are HIV-positive. The rest are the same patients you'd see at any family practice. Since the HIV-positive patients make more office visits on average than the other patients, the visits of the HIV-positive patients are somewhat more than 20% of the total, but still it's a very different atmosphere than an HIV-only clinic where you can assume that everyone around you in the waiting room is there for HIV. He sees that as a positive, as HIV patients can simply feel like patients, and not like there's some stigma about them where they have to be separated from other patients.

Has he lost patients because of his HIV work, because of his non-discriminatory approach, because some people might identify him as the "AIDS doctor"? No doubt. As an example he remembers a Detroit police officer from many years ago. He'd treated the man and his family for quite some time, until one day the officer came to him and told him that he'd arrested a junkie with needles and Dr. Benson's business card in his pockets, and that that had brought home to him that he really wasn't comfortable bringing his family to him anymore.

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But it's important not to exaggerate that. The number of people who would not choose him as their doctor specifically because of his HIV work is likely small. After all, he's had a thriving practice for decades, so apparently it's not keeping all that many people away.

Plus you never know how many people might have a higher opinion of him and be more likely to choose him as their doctor precisely because of his HIV work, perhaps because he cared for a loved one of theirs. So let's balance out the cop anecdote with another: He treated an elderly couple for many years before they passed away. One day they came to him and told him, "God bless you Dr. Benson for your work with HIV patients. We really love you for that. We have a wheelchair we'd like to give you if any of your patients need it." And they're not the only patients who have verbalized their appreciation for his devotion to his HIV work.

But in the end, even if the numbers turn out to be such that there are more people who are turned off by his practice being fully open to gays, transgendered people, IV drug users, whatever, again he's quite happy for such people to find a different doctor.

One of the things he most values about the international AIDS conferences he attends each year is gaining a greater understanding of how different cultures deal with these social issues that can be so crucial in combating HIV. He finds that many countries are significantly ahead of the United States as far as discrimination against certain populations, whereas others are decidedly worse. There is much that countries could learn from each other in this area.

Dr. Benson's experience and comfort level with people of all kinds—mainstream and marginalized—assists communication and diagnosis. By knowing how to talk to people the right way, what to look for, what questions to ask and how to ask them, he has made many diagnoses that were missed by another primary care doctor or hospital emergency room personnel.

Another sense in which it is far too early to declare victory over HIV is compliance imperfections. As noted above, studies consistently show that HIV-positive people who take their medication as directed have nearly the same life expectancy as HIV-negative people, and that high-risk HIV-negative people who take their preventive medication as directed generally remain HIV-negative. But the problem is that people don't always take their medication as directed.

For example, in the aforementioned iPrEx study of Truvada as a preventive drug, investigators were able to measure the drug level in the subjects and in that way ascertain if they were really taking their medication every day like they were supposed to.

Overall, the rate at which people became HIV-positive was 46% lower for those given Truvada compared to those given a placebo. Pretty good, but nowhere near as good as you'd like.

But for just the subset of people who were really taking their pill every day, the difference was 92%.

As Dr. Benson says, whether your medication is for treatment or prevention, you absolutely have to take it every day "like your life depends on it." The half-life of an HIV virus is only about six hours. If you miss even a dose or two you can allow the virus to develop resistance, and once the virus develops resistance, "then all bets are off."

Psychologically, people get pill fatigue. They take their medication for a long time and nothing happens, and though of course that means it's working, and intellectually they may well realize that's what it means, it feels like it's not making a difference because they always feel the same. So the sense of urgency lessens and they may well slack off.

It sounds easy to take a pill every day, but if you're 20 or 25, and you have a hectic lifestyle, and maybe you don't come home every night, you can miss one here and there. That is if you don't indeed train yourself to take this seriously as a life or death matter.

Drug compliance is one of the reasons it's so important for HIV specialists to maintain great relationships with their patients. As Dr. Benson describes it, you have to cajole them, remind them, do whatever it takes to get them to comply with their medication regimen. You have to have the kind of relationship where you can be honest with them and you can be confident that they're being honest with you. You have to be their "health coach."

It also helps to have the right team. Dr. Benson has partnered with an organization called Matrix Human Services that provides him with two case care managers, one or the other of which is in the office every day. These case care managers meet with the patients to help them with social issues, mental health issues, substance abuse issues, etc.—the kinds of things that can lead patients to put themselves at greater risk.

Imperfect compliance can be even more of a hazard for those patients who have a more challenging regimen than the newly diagnosed patients who only have to take one pill a day.

Some patients may have been diagnosed twenty years ago and not started their treatment with the kind of advanced protease inhibitors that are available today. Other patients may have skipped some days with their medication. In either

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type of case, they may now be dealing with HIV that has developed resistance. Such patients can still be treated, but it becomes more complicated. They may have to take six or eight pills instead of one, they may have to take pills twice a day instead of once a day, etc. More pills and/or more frequency means more opportunities to miss a pill.

That's why the three-month or nine-month injection will be such an important advance. It won't eliminate compliance failures, but it should make them considerably less common.

Of course a vaccine would be even better. The HIV prevention medications we have now or that are in the pipeline are prophylactics that only work while you're taking them, like when people take Malarone as a malaria preventive when they're traveling to a part of the world where there is a significant malaria risk. They aren't like a vaccine that triggers your immune system to produce antibodies to ward off any future infection.

But, Dr. Benson says, we really aren't very close to an HIV vaccine. That's another limitation of the "good news" of recent years in the fight against HIV. Research continues, trials are underway, but he says it's unlikely they will be fruitful in the foreseeable future. The HIV virus just mutates too readily.

So expect drug compliance issues to remain an emphasis of HIV specialists.

Then there is also the issue of access to health care and medication. The Ryan White program means that Americans can now get the care they need regardless of how much money they have. But of course HIV is an international problem, and what is true in the United States is not true everywhere. Again this is more of a social and economic matter, but in countries that are poor, or countries that have particularly regressive attitudes toward gays, transgendered people and other high risk populations, people don't always have that same access to the care they need for HIV prevention and treatment.

As Dr. Benson notes, sometimes it seems the purely medical

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How Does a Family Medicine Practitioner Become an HIV Specialist?

If people, perhaps even including other doctors, were asked what type of specialist is most appropriate to treat people with HIV, probably the majority would guess an infectious disease specialist.

And certainly there are some infectious disease specialists who focus on HIV patients in their practices. But as Dr. Benson points out, HIV specialists come from many different areas of medicine. He's met many dermatologists, nephrologists, and others who have become HIV specialists. The American Academy of HIV Medicine does not require one to come from any particular specialty for its certification, you just have to know HIV and pass the board-certification test every two years.

Especially since the introduction of protease inhibitors that have made HIV a chronic, manageable disease, not only do HIV specialists not have to be infectious disease doctors, but Dr. Benson makes the case that that's not even the most beneficial background.

As he says, treating HIV itself is the easy part. The problem is that as people are living longer with HIV, they have more co-morbidities. People who are HIV-positive—even when the virus is successfully suppressed—live in a chronic inflammatory state, and that itself has numerous health consequences. "When you're living with chronic inflammation, small problems become larger problems. You can't just treat the virus and ignore the co-morbidities."

HIV-positive people are more prone to coronary artery disease, diabetes, osteoporosis, high blood pressure, hyperlipidemia, hypogonadism, etc. They get these things at an earlier age, and with greater severity. In fact, more HIV-positive people die nowadays from the co-morbidities than from HIV.

Infectious disease doctors treat infectious diseases. They aren't specialists when it comes to all these other conditions that can stem from HIV. A primary care or family doctor like Dr. Benson has a lot more experience and is a lot more comfortable treating things like diabetes and high blood pressure.

That's not to say there is no role for an infectious disease specialist in the care of HIV patients. When Dr. Benson has a patient with advanced AIDS with opportunistic diseases, he does not hesitate to call in an infectious disease specialist. But those are rare cases today. For the day-to-day management of the bulk of HIV patients, the skills and training of a family doctor are as valuable or more so than those of any other specialist.

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aspect of providing HIV care is the easiest part.

So we've come a long, long way, but the picture is not entirely rosy, and there is still a considerable distance remaining.

The work continues. The World Health Organization has organized its HIV efforts around its "90-90-90" plan. The goal is by 2020 for 90% of HIV-positive people in the world to know their status, for 90% of those who know their status to be receiving treatment, and for 90% of those receiving treatment to have the treatment succeed in achieving viral suppression. It is estimated that if these goals are reached, then within ten years—by 2030—we should reach a numerical turning point where the number of people newly

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Now Hiring: HIV Specialist

The HIV specialist community is a very small, strong network. They are people who have engaged in the same quest for years, attended the same meetings, often participated in the same research. They share best practices, horror stories, etc. Many strong friendships have formed. It is a community marked by camaraderie, not competition.

It is also an aging community. One of the ironies of the successes of the battle against HIV is that the fight has lost some of its urgency and now we may be facing a shortage of HIV specialists.

HIV work is not the kind of crusade it was for many in the ACT UP era. The number of idealistic young doctors taking up HIV work in order to be involved in the fight for justice has dwindled steadily over the years as AIDS has left the headlines. Fewer people who take up medicine today do so because they watched a friend or family member die of AIDS and were inspired to join the fight against HIV.

Not to mention it has never been a lucrative specialty. As Dr. Benson describes it, it's the kind of labor-intensive specialty that places a premium on using one's mind and on practicing good people skills more than on performing procedures, and it's in procedures that the money lies. 80% of the cost of caring for an HIV patient is pharmaceutical bills.

Dr. Benson reports that every time he gets together with other HIV specialists, sooner or later the talk turns to what will happen when they—the dinosaurs—retire. To whom will they pass the torch? Where are the new doctors with that same passion for HIV treatment?

Because that's what you need more than anything to truly excel in this area of medicine. As Dr. Benson says, "What does it take to become an HIV specialist? I can give you one word for that: Passion."

Dr. Benson has long been interested in bringing another young doctor into his practice that he could mentor as an HIV specialist. He's getting older and doesn't expect to practice for many more years. He wants to gradually slow down and turn the practice over to someone with that passion for HIV so he can know that his patients are in good hands. But so far it hasn't happened.

Students rotate through the practice all the time, and they consistently find it a fascinating, eye-opening experience. They learn about lifestyles they'd never been exposed to, and they leave as much better physicians because of the diversity of what they've experienced in his practice. Yet when the time comes to decide on a specialty, they always seem to go in a different direction.

HIV has not been defeated. Looking at the situation optimistically you can say that we are in the process of defeating HIV, but that's a lot different. The need remains for top quality medical professionals to join the fight. Whatever loss of urgency there has been is not justified.

In its way, HIV can be one of the most challenging of specialties, and certainly not one of the most lucrative. Yet at the same time, as one who has fought the good fight since 1980, Dr. Benson will tell you from experience that it is also one of the most fulfilling.

The members of our MHP community know countless young doctors and soon-to-be doctors. These may be family members, friends, certainly many students. With your help, perhaps the best thing that could come from this article would be if getting the word out results in Dr. Benson finding that passionate, idealistic young protégé he longs for.

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becoming HIV-positive will be less than the number of HIV-positive people dying (not necessarily of HIV, but just of old age or other issues), and hence the total number of HIV-positive people in the world will begin its decline.

Dr. Benson is optimistic. "I feel fortunate to have been around for the beginning of an epidemic, and now to see nearly the end of an epidemic."

It certainly hasn't been the career young Dr. Benson envisioned in 1980. How could anyone have imagined such a journey? But he looks back with appreciation on the education he received and the contributions he was able to make: "HIV gave me a lot of respect for patients, and human life. It gave me a greater understanding of the stigma attached to certain groups, including for sexual orientation and lifestyle.

"HIV really changed my life."