

## **Introduction**

Imagine a virus that mutates with each person, a virus that has no warning signs and once it is discovered it is a life long battle. This is what millions of people around the world face. This virus is HIV/AIDS.

I have always been interested in science; for a while I have wanted to know more about HIV and AIDS. I don't really know what sparked my interest in the vast topic of AIDS, but whatever that event was, I've been thinking about HIV/AIDS a lot ever since. The reason I choose HIV/AIDS is because I really have a huge interest in almost everything about it, I wanted to know what it does to the body, the cultural history, and how HIV becomes to AIDS, and what happens next. I wanted to know how a person changes or doesn't after learning they are HIV positive, I also wanted to know if there has been any studies about how someone emotionally reacts to learning they are HIV positive. I knew this topic would hold my interest for the duration of the project because there was so much for me to learn and there were so many resources that I could use.

To begin, I honestly didn't really know all that much about HIV and AIDS. But, I did know that HIV can be spread through body fluids, such as semen or blood. I knew this after many years of my mother explaining AIDS to me. I also knew that it can take many years for HIV to develop into AIDS; again I knew this because my mother has explained all I know about AIDS to me. Also, I knew AIDS affected the immune system. I hoped by doing this project I would learn more about AIDS.

There were many questions I had about HIV and AIDS. I wanted to know what it is like learning you are HIV positive? What have you changed about your life? Do you feel like you are a different person now? What kind of research is being done to help find a

cure for AIDS? What makes HIV become AIDS? Is there a scientific field of research dedicated just to finding a cure, or a vaccine? Where is most of the research being done? These are just some of the questions I wanted answered, mostly I wanted to know what it is like to be HIV positive and what research is being done on AIDS. A few experiences I wanted to have would be to meet someone who is HIV positive and to volunteer at a clinic where needle exchange programs happen. I wanted in addition the opportunity to talk to someone who is working on a vaccine or is doing active research. In addition, I would like to interview a scientific researcher who focuses on HIV/AIDS., I thought the interview would be interesting because I wanted to hear their point of view on the epidemic and why they went into that particular field of research.. I knew that I would learn a lot thought this project, and I was really excited to start.

I thought this project on AIDS/HIV would impact me greatly in many ways. I knew as a citizen and as a thinker I would be more informed. I've always really loved science so I think maybe after this project I will either love science more, or absolutely hate it. I thought I would love science even more, and most likely will end up as a researcher for HIV/AIDS and try to find an antidote for it, but that's just a thought. I thought this project would open my eyes to a new world of science, and hopefully I would enjoy it.

### **Story of the Search:**

#### **The History of HIV/AIDS**

In the year 1981, the world was a new place. It was a new decade, and in the science world, there was an area of concern. In that year, the first cases of HIV were reported. The first five cases were five gay men, so the disease was known as GRID, or Gay Related Immune Deficiency. Since 1981 the disease has become world known, and caused an

uproar politically and socially, and has become a huge part of the cultural landscape of the world. In the first years of the disease it wasn't very accepted, especially by the general public and the government. Since then though, the knowledge of the virus has grown enormously socially and scientifically in the last 29 years since the first cases (McElrath 154-265).

In February of 1982, the Center for Disease and Prevention reported that 251 men were "GRID" positive. Since not much was known about the disease, the people who had it were essentially told they would die soon. By 1987, of the initial 251 people who were "GRID positive" 99 had died, there were so many deaths because there was no knowledge about what was happening to the people. It was soon discovered that men and women who injected drugs, or IDU's, were at risk along with hemophiliacs for being affected by the disease; at that point it was no longer just the "gay cancer". After GRID became an inaccurate description of the disease, it was termed AIDS, or Acquired Immune Deficiency Syndrome. Also, it was soon discovered that other bodily fluids transmitted HIV, the initial infection that leads to AIDS. (McElrath 154-265).

In the early years of AIDS, the ways that scientists thought HIV was transmitted seem silly now. It has been proven that HIV is transmitted by bodily fluids such as blood, semen and vaginal fluid. There are a number of ways this can happen, including sharing needles with someone who is HIV positive, having some sexual contact with someone who is infected and when an infected mother breast feeds her baby. There are a few less common ways to become infected, including being bitten by someone who is HIV positive, receiving a blood transfusion and tattoo and body piercing hold a small risk for transmitting HIV, if the needles aren't clean. There are also myths about spreading

HIV, such as HIV being spread by air or water. Other false ideas about HIV transmission are being spread by insects, saliva tears and sweat closed mouth or social kissing or casual contact such as sharing dishes or shaking hands are also myths (“Centers for Disease Control and Prevention”).

### **Demographics**

Since the year 1981 the demographics for HIV have changed from just gay men. According to the CDC gay men along with IDUs and prostitutes were among the groups at high risk. Between the years 1987 and 1999, the number of cases of AIDS was 733,374. In 1998 it was estimated that 400,000 new infections would occur that year. In 2006 the CDC estimated that 56,000 new infections occurred. In 2007, 74% of the people infected were men and 26% were women. The two highest transmission groups were high-risk heterosexual contact with 32% of the infections and male-to-male sexual contact with 53% of the total infections. The category of male adults and adolescents, 71% of the new infections came from male-to-male sexual contact. The adult female and adolescent group, 83% of the infections came from high-risk heterosexual contact. By race, the two highest groups are African Americans with 51% of the infected population and whites with 29%. By age group, 20-29 is 25%, 30-39 is 26% and 40-49 is 27% of the infected population (“Centers for Disease Control and Prevention”).

### **Testing and Research**

The most common test for HIV is a rapid test; this is one that detects HIV antibodies, the substances the body creates in response to becoming infected with HIV. Most people develop detectable antibodies between 2 and 8 weeks after being infected. The rapid test only takes about 20 minutes to give results. Conventional HIV tests need

to be sent to a lab to be tested, and can take about a week or two for the results. The only symptom of HIV occurs within a few weeks of transmission, and only some people experience, is developing flu-like symptoms. People living with HIV can feel healthy for years, without developing AIDS, but their body is still is being affected (Centers for Disease Control and Prevention’')

In the years since HIV/AIDS was discovered, there have been many conspiracies as to how HIV/AIDS started. Since then though, scientist has confirmed that chimpanzees in West Africa are the source of AIDS in humans. Since 1981 when the government wanted nothing to do with HIV/AIDS, now 19% of the federal budget goes to AIDS research. There are seven institutes that focus the most on AIDS research, they are as follows: The National Institute of Allergy and Infectious Diseases, The National Cancer Institute, The National Institute of Drug Abuse, The National Center for Research Resources, The National Institute of Mental Health, The National Institute of Child Health and Human Development and The National Heart, Lung, and Blood Institute. (McElrath 154-265)

### **Interview with Sharon Stranford**

Susan Strandon is the professor of biological sciences at Mount Holyoke College in South Hadley. I found Sharon when I was looking through the course catalogue trying to find a class or lecture to sit in on, instead of finding a class, I found an interview.

When I arrived at Sharon Stranford’s house I was greeted by a large white cat. Sharon was on the phone, so I stood awkwardly in the door way for a few minutes. Once she was off the phone we went to her back porch to do the interview, we were joined by the cat whose name I never found out.

Sharon Stranford was trained as an immunologist, which she got her PhD in. “I studied HIV/AIDS as a way to see how the immune system was supposed to work”. Sharon did two “post docs” which are what someone does after they get their PhD at Oxford University in England and at the University of California San Francisco. A University of California San Francisco is where she had the most “active role” in the research community. It was at UCSF that she began her study of HIV/AIDS, “in an HIV lab that worked with human patients, in particular high risk populations.” Sharon focused on people who were at high risk and were exposed, but didn’t contract the virus. “The question I was asking was, what was it about their immune system that was activated to resist the virus”? What I found to be the most interesting thing I learned during the interview was that there are in fact people whose bodies can be exposed to the virus and not contract it. “There are people who have some natural resistance because they have inherited a mutation in a gene that’s important for the virus to actually get into your cells”. Unfortunately, these people are not completely protected. “95% of the [HIV] viruses use this cell receptor to get in, but 2% to 5% use a different cell to get in”. What is also shocking is that some people the more they are exposed, the chances of them getting it go down.

Currently, Sharon is working at Mt. Holyoke University where she is working on MAIDS, or mouse AIDS. Mouse AIDS is a virus much like human AIDS, but somewhat different, this is what scientist use to study so they can be protected from the actual virus. The mouse version is just as good to research because it is similar to the human version but humans can study it safely Sharon is working, along with many other scientists all over the world, on trying to find a cure or vaccine for HIV/AIDS. “It is more of a

tractable goal to either keep people from getting the virus or once they are infected to suppress the virus”. Working with mice is also easier for research reasons along with safety reasons. “We can infect them and look at their white blood cells and the bulk of their immune system in the first hour”. It amazed me how not 15 years ago this would have been impossible to do. I did feel a little bad for the mice, but at least they got their own name, MAIDS.

Sharon mentioned that the most rewarding part of her job as a professor is seeing her students really enjoy what they are learning. She also said that her favorite part of research is the “puzzle of science”. This is also my favorite part of science, it’s a little like algebra in the sense that scientists take all they know to find the unknown. I guess it’s a fitting because science and math go hand in hand.

Sharon hopes that my generation focuses “more on prevention”, also, “more realization that HIV is only one STD, and to be cautious about sharing fluids”. What Sharon hopes for my generation mostly, is to completely erase mother to child transmission. “There is no reason that we can’t put out the money that would be necessary to make sure that no child has to be HIV infected at birth”. This completely shocked me, mostly because I’d never heard anyone mention this, it seems so easy.

The interview was cut a little short because Sharon was leaving for a family vacation. But even though it was short, about a half a hour it was very informative and helpful. I really enjoyed the interview because I learned so much from a friendly stranger. Sharon invited me to email her so I could visit her lab over my break.

Overall I was happy with the interview, I wish Sharon and I had connected a little more, and had more of a conversation as opposed to me just asking her questions. I wish

the interview was a little longer, but as I said, she and her family were leaving for a vacation later that day.

### **Interview with Becky Hawes-Sivitz**

I found Becky not completely on my own, she was a former employee of my mothers and she still worked in the same building as my mother. I was given the number to her office, and set up the interview. Becky is an HIV/AIDS case manager, which means she helps people who are HIV or AIDS positive manage their life. This can mean anything from helping get pills to helping find a job.

I arrived to Becky's office a few minutes early, mostly because I was nervous about being late, like I was for my last interview. Becky met me in the hallway to her office and it look like she had been working on some paperwork when I entered her office. I have known Becky for a few years because she worked for my mother as a consoler at Tapestry Health in the Greenfield office before she took the job she now has, for the time being. Becky is leaving Tapestry Health for Graduate School in late May.

My first question was what exactly her job description was; she said that her job title was an HIV/AIDS Case Manager. I felt a little silly asking her that because I realized I could have just asked my mother. She described that this particular section of the HIV/AIDS division focused mostly on HIV client services. Becky then went on to explain that her office took a "holistic view", which meant that they help clients pay for rent or to apply to programs that help pay for medications. She said the biggest affect her job has had on her is how she sees people. Becky also mentioned "it has been very eye opening to me to see the differences between me and my clients and how there really are very few differences between us".

I asked Becky about her view of HIV since she took the job of HIV/AIDS case manager, after a pause she replied “at this point, HIV/AIDS is more of a chronic illness, people now are living long lives with relatively good health throughout”. When asked what was scarier about HIV/AIDS Becky responded “how disproportionately HIV affects minorities of race and class. It has given me a passion to work with people who are underprivileged”. Becky has noticed trends in regards to her clients. “A lot of people who have a history of drug and alcohol abuse, people who were living in poverty or grew up in poverty. A large portion [of the clients] are men who have sex with men”. Even though MSM or men who have sex with men is a large portion of the people who are infected with HIV this group, at least at Tapestry, this is the group that needs the least amount of services. “A lot of our clients come from really poor back rounds or relationships where they weren’t using condoms because they were being abused, or sharing needles because they were fending for their next fix”.

When I asked what her favorite personal experience was, Becky’s face lit up a bit. She then went on to tell me about a couple who are clients of hers. “Each client exposes me to different things that are incredible. I have these two clients who are both from Puerto Rico. I first started working with the woman who was just an absolute mess; she was having panic attacks and really just breaking down on an emotional level and was just terrified that she was dying right then and there. She’d found out that she was HIV positive when her husband died of HIV. She didn’t even know he had HIV until he was hospitalized. She met her now fiancée, the two of them are both our clients. When they met they were both HIV positive, and they have both really utilized our services and I think I have a really great relationship with the two of them. I was talking to them the

other day about me leaving and the three of us started crying. I was just saying to them I couldn't believe how far they've come. They've gotten their life together and as far as financially, they are fixing the issues they are having with their landlord not fixing up their apartment, it's not livable, and they've gotten legal assistance with that. They both are taking their medication, and they are doing great. He was an alcoholic and he's been clean and sober for 8 months. They're just so in love, it touches your heart to see them together. It's been really wonderful to see them empowered, and I think that is what allows people to live with HIV and not stop taking their medication." Listening to Becky talk about this couple showed me how much she enjoyed her job and how what she does is so important. This also made me realize that what she does is something that I might want to do just because of how important her work is to her clients.

What I found funny is that HIV/AIDS wasn't something that Becky was interested in before she started working at Tapestry. "I find infectious disease fascinating on a biological level, and I think HIV is a crossroad of social injustice and infectious disease. Honestly, until I started working here I was terrified of HIV. I didn't want to think about it, it was too scary. I didn't want to think about my own risk and the people in my life's risk. I was scared to work with people who had HIV, I was scared my fear would show and make them feel bad, or I was going to say something offensive, or even that I was at higher risk for getting HIV. Getting in a position at a job that challenged me in those areas is what made me grow more as a person". It was shocking to hear someone be so honest about themselves and their own fears. I applaud Becky for being so open with me about her fears of HIV; it was nice to think about how much her opinion of HIV has changed.

As mentioned, Becky worked for my mother as a counselor, and part of her job was HIV testing. “Testing for HIV was scary. Testing someone for HIV you are dealing with their fear. You have to put yourself in a position as a counselor, where you can be supportive of them when they are feeling fearful. In this job, I really don’t have to do that as much. I do have to let go of any stigma and meet people where they’re at. That’s incorporated in counseling. I remember when I was interviewed, when your mom interviewed me, and she asked something along the lines of what I was most scared about the job, and I remember replying I was scared to tell someone they were HIV positive. I never had to tell someone they were diagnosed with HIV. I think I’ve told 8 or 10 people that they *might* have HIV after the reactor test. Which is probably worse in some way you are telling someone ‘Hey, you get to have the worst week and half of your life’ I never had any of my reactive HIV screening tests come back as positive. My co-worker Meghan, she had to tell someone they were HIV positive. I know that was a really emotional experience for her. One thing she said about it was the person already knew they had HIV, which is actually really common. Most of the people I’ve talked to who have given an HIV positive result have had the person be suspicious they had HIV; they had some inkling that something wasn’t right, but that obviously isn’t true for everybody. One time after I had a reactive test I took two days off, it was just totally emotional. This person that I was working with, his fear turned into anger and it was really scary, and his anger could have very possibly turned violent”. Hearing Becky talk about telling people they are HIV positive it made me wonder what I would do in a situation similar.

“The real stinker about HIV is the stigma around it. At this point, with all the medications, there isn’t much of a difference between HIV and diabetes, other than the way people get HIV and the way people get diabetes. You don’t tell someone they have diabetes and get the same response as when you tell someone they have HIV. With HIV people just assume they’ll never have a partner again, no one will ever love them and they’ll constantly have to choose to tell people or not, to be HIV positive and be able to date. One thing I do have to say is that before coming to this job I had this idea that a lot of people who are HIV positive don’t tell their partner, I’ve encountered the complete opposite. They are by far much more responsible and conscientious of other people than most people are because they know what it means for someone else to put their body at risk, so they really don’t want to do that anybody else.” Becky then told me about a client of hers, who is a crack addict, who called her one time really upset because one of her former friends sold her a macadamia nut, when she told her it was crack. When Becky asked her why she was upset about this she said “what bothered me is my friend lied to me, and that I would never do that to her”.

When asked if her job was stressful, Becky paused for a minute. “Yes, it can be in ways that I’m sure that other jobs aren’t. Dealing with client’s emotional stuff can be really stressful. I’ve had clients who call, and like freak out on me and scream and hang up. And then, like two hours later, call me back and apologize. I’ve had clients do all kinds of crazy things. I have to constantly be professional and not react how I would in my real life. But, at the same time, its less stressful than other jobs, I’m sure because I’m working with people, so it’s at that speed. You can’t rush people to change, so when I let go of my expectations for a client, it’s not stressful”.

I knew before I asked the question what the response would be, but I wanted to know exactly what made Becky's job rewarding. "Completely. I want to do this kind of work because of how rewarding it is. I have this client whose dynamic is really hard for me to work with. I was working with her doing something that was really difficult for her, and having a really hard time. We got through it, and I said 'we did really well today; I'm feeling good about how things went'. She then asked me if I knew if she was a singer. I said I didn't. She asked me if it was okay if she sang for me. She then sang Whitney Houston's "I'll Always Love You" and just killed it! And I almost stared crying. So, yes my job is rewarding". Becky amazed me at how much she truly loves her job and how important it is to her. Most adults I know like their job well enough, but Becky seemed really passionate. It gave me hope that someday I will be doing something that not only is important, but challenging and rewarding. Hopefully, I'll love my future job as much as she loves her job. When I asked her what her least favorite part of her job was, Becky laughed and replied simply, "all the paperwork".

At the end of the interview Becky gave me the number of one of her clients, after asking him first, to interview. I was so happy with the interview because I got such a picture of what Becky does and a view of what her opinion of her job. My mother told me that Becky called her a few days after the interview to say that she too enjoyed the interview.

### **Interview with Anonymous**

On my last interview, with Becky Hawes-Sivitz, she gave me the number of one of her clients who was HIV positive. When I called the client, who wished to remain anonymous, he only had a few minutes to spare. I really just wanted to have a short

conversation with him about when he found out he was HIV positive, and that was what I got.

He found out he was HIV positive about fifteen or twenty years ago, when he was forty. When he found out that he was HIV positive he said he “was pretty surprised and mad”. I imagine this is how it goes for most people who find out they are HIV positive, I know some people sometimes almost expect it, but when it comes as a complete surprise, it must make things a hundred times worse.

He told his family almost immediately after he found out, and when he did “one of my aunts passed out. My family was completely shocked, my mom was pretty upset”. I can’t even imagine telling my family something like this; it probably is one of the hardest things someone would have to do. Also, I imagine that most people who are HIV positive might wait a little while before telling their family, I know I would wait probably years just out of fear.

He found out that he was HIV positive about fifteen or twenty years ago when the view of HIV was much different than it is today. “I feel fortunate to be in a time when there are so many medications that are available”. There have been so many advancements in years since he found out he had HIV that living, not dying, from HIV is more of a possibility. “It’s not the killer it used to be, I feel fortunate about the new medications that are around today. I used to take 18 pills a day, and now I only take one”. That is also the thing about how HIV has changed in the years since he was diagnosed with HIV, is there are so many treatment options that living with HIV is easier.

At that point he had to go, but I was thankful that he gave me his time even though he was busy. The interview lasted a little less than six minutes, but I am grateful that I got to talk to someone who is HIV positive.

### **Significance**

Through out the I Search, I learned many things that I didn't expect. I learned that HIV mutates with each person, and that is why it has been so difficult for there to be a cure or vaccine. Also, I learned that there are some people who are immune to the disease, meaning that the more they are exposed to the virus, the less likely they are to get it. This only happens to people who are at extremely high risk and are exposed often, usually prostitutes are the most common people who develop this immunity. Most of the questions I had were answered, but I really would like to do the volunteer work I mentioned, although I am currently on the information and education committee. All three of the interviews I had were really informative, and gave me a good sense of what the three people did for the AIDS community. Each of the interviews gave me a different perspective of the virus; one interview was with the human services point of view, one interview gave me a personal glance into what it really means to live, not die, with HIV, and another gave me the medical perspective of the virus. Each interview was good on its own, but as a collective, they all become better.

### **Conclusion**

The I Search was really important for me on many levels. One being, that I really didn't know how interested I was in public health until now. Public health is making sure the general public was healthy, and this means doing anything from family planning to researching HIV/AIDS. Doing the interviews helped me work on my phone

conversation skills and helped me realize that talking to people I don't know isn't that scary. Also, I learned how important it is to stay organized and timely with all my work. Having deadlines has been really good for me; they made me really have to work on my time management skills. Through research and interviews I learned that I like learning from interviews and experiences. Through learning about HIV/AIDS my mother and I got a chance to discuss something that most adults don't talk in depth with each other about (my mother works at a place where HIV testing happens and who knows a good amount of information about HIV/AIDS herself). It was interesting to her about her experiences with the virus and what it can do. I realized through the I Search how interested I am in science and public health. I think being given the chance to do the I-Search has opened my eyes to new perspectives and ways of life.

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