

Jake: Hi everyone! Today I am with Dr. Volberding to discuss AIDS and HIV. To start, would you like to introduce yourself?

Dr. Volberding: Hi! I'm Paul Volberding, an emeritus professor of medicine at the University of California San Francisco. I've been involved with AIDS and HIV for many, many years.

Jake: To begin, I've read that you were initially trained in medical oncology, so I was curious what made you decide to focus on HIV/AIDS.

Dr. Volberding: So I was trained in oncology, but I was always really interested in working at the bench in the lab working with viruses. I was always interested in viruses ever since I was an undergraduate at the University of Chicago. I pursued oncology because at the time viruses were thought to be a cause of cancer. So that was my research background. When I started as a faculty at UCSF at San Francisco General Hospital, I began to see patients with what eventually would be called AIDS but this was 1981 before it was called AIDS. Over half of the patients we saw at first had cancer, especially kaposi sarcoma, so I began taking care of the lymphomas and the kaposi sarcoma. As we realized more and more that this was likely due to a viral infection, my training in virology helped me a lot. Especially, at first, I focused on the intersection between cancer and AIDS.

Jake: Oh, so you were there from the beginning. I've read and heard about the stigma that, while still exists today, was extremely prevalent at the beginning. How has that shaped your experiences with this disease and people who have it?

Dr. Volberding: The stigma has and remains a huge problem for people with HIV. In San Francisco, itself, it was less of a problem with it being a real liberal city emphasizing tolerance. Even here, it was an issue. People were afraid especially of having people know they had the virus. Families were often unaware their son was gay, much less that he had AIDS. It was a huge problem and led many people to avoid being tested as they were afraid of the stigma. Even today, it has led many people to avoid taking the medicine as they don't want people to know they have AIDS. It has been a real challenge, and less-so in San Francisco but especially in many rural areas.

Jake: Oh wow. I guess that leads to my next question. DiscussMed is heavy on advocacy which is the process of creating attention about a specific cause. I think that for a disease like HIV and AIDS, advocacy is especially important in helping break or reduce the stigma. I know you have been a part of a few organizations, so can you talk about your experiences with advocacy organizations?

Dr. Volberding: Advocacy and HIV have been really partners from the start. The disease initially affected people who didn't have much in the way of a conventional family if you will, often gay men living more or less solitary lives, they often relied on the community and community organizations to provide a lot of that care. As a physician working with these patients, I worked for many of these organizations and helped start some because our patients needed so much help and needed so much information. It was a really important part in how we responded to the AIDS epidemic domestically and internationally.

Jake: With your experience in advocacy, what are some methods of advocacy that you have found to be extremely effective in fighting AIDS?

Dr. Volberding: Probably the biggest issue right now is keeping people aware that there is still an HIV and AIDS epidemic which disproportionately affects young men and people of color. Having a deep reach in organizations that reach these communities are great. Many of the advocacy organizations in AIDS have increasingly recognized the importance of reaching such communities. There are many opportunities to get involved in these communities through volunteer work to reach these communities. Help is needed in all areas especially with disseminating information through brochures and social media. I think that unlike COVID-19 which is fraught with misinformation, HIV and AIDS there is complicated and changing information so disseminating it is important.

Jake: Speaking of organizational based activity and advocacy, I was sort of surprised to find, I guess, relatively fewer organizations devoted to HIV and AIDS advocacy as compared to some other causes. What are some organizations that you recommend and have found great success?

Dr. Volberding: Well, if one is interested in issues concerning the LGBTQ+ community, places like the Human Rights Campaign that provides national advocacy for LGBTQ+ issues, not just AIDS. There are also many professional

organizations that do work with HIV and AIDS. I'm involved with one called the International Antiviral Society USA. There are organizations associated with the World Health Organization and with the United Nations, for example UNAIDS, which do a lot of work internationally. I think that is a great place to start. There are also government organizations like the CDC which do a lot of work with this disease. I think turning to those for their suggestions would be useful.

Jake: That's interesting. Wow, that was very thorough insight, and I think this will hopefully provide anyone that doesn't know where to start, a great place to look. Now, switching gears a bit, advocacy goes hand-in-hand with fundraising especially for research, and I often like to group them together all under the umbrella of advocacy. I know that you have a heavy background in research especially as you used to run the AIDS Research Institute at UCSF.

Dr. Volberding: I am now retired from the university, but yeah, I used to direct a lot of the organizations relating to HIV and AIDS here at UCSF, but I would say that contributing to HIV and AIDS research is good, but I actually think contributing both in terms of time and financially to organizations that provide services to people might be more reward and useful. There is quite a bit of funding for AIDS research especially from the NIH.

Jake: Yeah, I agree with it being more rewarding, but I also think it's more doable- it's pretty hard to get involved in research.

Dr. Volberding: Absolutely and as someone who wants to get involved and make an impact in the fight, it is nice to see the benefits of your work and contributing more immediately. I would tend to direct people, especially young people, to get involved directly with the people through organizations that focus on activities such as communicating with young people of color is an area of need in HIV.

Jake: And I've read that speaking of people of color, HIV and AIDS tends to be more prevalent in specific communities such as the African American community. Why is that?

Dr. Volberding: That's a really, really excellent question that people spend their lives devoted to. Because of systemic racism, marginalized communities have been denied access to healthcare for hundreds of years and often find themselves out of

the mainstream and ignored by the mainstream medical establishments and often ignored when it comes to research. There are any number of issues such as the stigma in communities of people of color which is particularly terrible. There is a major epidemic of HIV and AIDs in southeast African American rural communities. It comes down to traditional lack of access to healthcare, being ignored by the political establishment and others, and not having financial resources. The list goes on and on. It is no secret that people of color in this country face daunting odds when it comes to their health and HIV is no exception to that.

Jake: Yeah, that makes a lot of sense. I always found it quite odd that HIV and AIDs tends to be more prevalent in specific marginalized communities especially since it isn't a genetic disease which does tend to run in specific communities. I guess what I sort of now want to focus on is the importance of research like yours as it sometimes goes behind the scenes, yet it plays an integral role in fighting diseases. So as a researcher yourself, do you mind quickly explaining the importance of research in the medical field.

Dr. Volberding: Oh sure. Research is hope. Research is the future. In the early epidemic of HIV and AIDS, people were desperate for any kind of knowledge and research is the way knowledge is expanded. Sometimes knowledge doesn't directly translate into hope, but it often does as people wonder what's happening to them and why a symptom occurs. Research answers those questions with knowledge which can provide reassurance and hope. HIV is a great example of the importance of research. In the span of relatively few years, we found the source of the virus, strikingly effective treatments, and amazing preventative measures. The only area where we haven't made great progress is in vaccine development, but in the area of diagnosis and treatment HIV and AIDS is nothing like what it used to be. When I first began seeing HIV and AIDS patients, if you had any symptoms of AIDS, you would die because we had no treatments. So very quickly treatment became hope, and treatment derived directly from research. So there was great support for research focusing directly on HIV and AIDS. That's been useful when we think of other challenges like the COVID-19 pandemic where we saw research developments at a striking speed like vaccine development. Research in all areas of medicine is where we get reason to hope and reason things are going to get better.

Jake: Yeah, I take part in research, and I have been working in a lab, and it's crazy how much is done and how advanced it has gotten. I know you mentioned HIV

vaccines as a focus of AIDS and HIV research, but what are some other areas of focus?

Dr. Volberding: I would say one of the major focuses of research right now is an area of science called implementation science where unlike learning basic things in a laboratory or making new sciences, it is about best applying what we already know to improve the outcome for as many people as possible. For example, we have very simple and very nontoxic medications which can almost completely prevent HIV infection. If you take one pill once a day of some of these medications and engage in high risk behavior, you still won't get infected. It is 100% effective. It is called PrEP, pre-exposure prophylaxis.

Jake: Yeah, I've heard about PrEP

Dr. Volberding: Research focusing on how to educate people how to use PrEP, why it is important, why it is important to take it on a regular basis, and so that area of research, I think, is some of the most important. It is very good we have treatments which can improve the life of those with HIV and AIDS, but it is even better to focus on helping people avoid getting the disease in the first place and that is what some of this research can do.

Jake: Yeah, so you mentioned the importance of spreading knowledge about HIV and AIDS to help prevent people from getting it in the first place. Do you think there is a place for advocacy in publicizing research about HIV and AIDS?

Dr. Volberding: Oh yeah. So I'm going to sound like I'm backtracking here. I think research is fundamentally important. It's what I've done my whole career, and I've said direct services may be where I focus. But there is an interface there between helping educate communities about the existence of PrEP, for example. It is in part research and in part service. It is not research in the sense of being in the laboratory but it is advancing knowledge and doing things better and more efficiently. There is a tremendous area for people volunteering in that field.

Jake: Yeah, so I guess my last question ties into that. The goal of DiscussMed is to build a niche bridge between pre-existing medical advocacy organizations and youth communities to get youth more involved. And I think publicizing research is a great place to get people involved. I always like to ask people when I interview them

what you think is the importance of getting youth involved in these advocacy efforts?

Dr. Volberding: As people become sexually active, being educated on the nature of sexually transmitted infections and the possibility for very healthy sexuality wouldn't just help HIV but all the other conditions we see. It would help young people become aware of Human Papillomavirus, HPV, in which there is a very effective vaccine which causes anal cancer after years in men and cervical cancer in women, and it is sexually transmitted. If we can help people better understand sexuality, reproductive rights, vaccine applications, you know there are so many areas where young people can make an impact. Having people think about how they are living their lives, what kinds of risk they are taking, and how to reduce the risks without denying the pleasure that a healthy life can provide. There is a real promise there.

Jake: I think that was a good note to end on. I like to be respectful of your time and thank you for speaking. Is there anything else you would like to say?

Dr. Volberding: I think you hit some really important areas and appreciate your dedication.

Jake: Ok, thank you again for coming. Have a great rest of your day!