WEBINAR VIDEO TRANSCRIPT
Improving Health Outcomes:
Moving Patients Along the HIV Care Continuum and Beyond
7 September 2016

ANNOUNCER: I would now like to turn the call over to your host for today, Miss Shelly Kowalczyk.

SHELLY KOWALCZYK: Thank you, Good afternoon, everyone. My name is Shelly Kowalczyk, and I will be moderating today's Improving Health Outcome, Moving Patients Along the HIV Care Continuum and Beyond webinar. This is the second in a three-part webinar series brought to you by the HRSA Special Projects of National Significance and the Integrating HIV Innovative Practices Project. So today's agenda, I'll be providing a brief overview about the Special Projects of National Significance or the SPNS Program and the Integrating HIV Innovative Practices or IHIP Project.

We are fortunate enough to have two speakers with us today to discuss their SPNS intervention. The first speaker will be Dr. Anne Rhodes who is the Director of HIV Surveillance at the Virginia Department of Health. And she'll be presenting on their active referral intervention. Dr. Rhodes oversees all HIV care prevention and surveillance data at the Health Department. Anne has worked to integrate multiple data systems for tracking outcome across the HIV continuum.

We will also hear from Valerie Robb, a registered nurse at the University of California, San Francisco, HIV AIDS clinic at Stan Francisco General Hospital. And she will be presenting on their hepatitis B treatment expansion initiative. Ms. Robb coordinates the hepatitis treatment program, and in that role has led patient education and support groups, provided team coordination and with SPNS support, assisted in the development of a dedicated viral hepatitis treatment clinic.

So just a brief overview here. The SPNS program reflects changes in the HIV epidemic. It also aligns with National HIV Policy Strategies, such as the national HIV/AIDS strategy, changes in the health care environment, and the SPNS program focuses on funding and supporting applicable and sustainable models of care. So the SPNS program advances the HIV care continuum to include all stages from diagnosis and linkage to viral suppression and beyond. As such, initiatives funded through the SPNS program have helped to advance people living with HIV along the continuum of care.
So one of the challenges first encountered with the SPNS program was effectively disseminating information about these successful models of care and lessons learned to really help providers in replicating and implementing these interventions. So as a result, the IHIP project was developed, designed to promote and disseminate these effective strategies and lessons learned, in order to again, support replication and optimal implementation of these successful models of care in their own practices.

And as a result, providers are more informed, there’s a stronger workforce, and ultimately, patients are healthier. The IHIP Project also helps to advance and support federal priorities and strategies. So the strategies for this IHIP Project include developing implementation tools and resources such as manuals, curricula, and pocket guides for providers, that are specific to the evidence informed interventions that the grantees have implemented.

For instance, the two speakers that we have today, their interventions are both being featured in a manual, an implementation manual that has been developed and is currently going through a clearance process, hopefully available to all of you in the coming months. In addition to those tools and resources, IHIP Project helps to disseminate information about those products to various stakeholders to ensure that you’re all aware of these tools. And we rely on various HRSA Listservs, the AETCs and other sources to distribute that information.

And then we also provide capacity building assistance to enhance the implementation of evidence informed SPNS interventions among the care providers. And these include webinars such as we’re conducting today in order to share information and engage in peer to peer sharing, also through conferences and meetings. We also have a dedicated e-newsletter, which we use to market the tools and resources, and an online collaborative platform. And at the end of these presentations, I'll provide a slide that has links to staying connected and joining, through these various Listservs and e-newsletters.

The IHIP resources are stored on the TARGET Center website. You can see here that you can access this Center at careattarget.org/ihip. And here you will find any forthcoming tools and resources that are currently being developed as well as a number of them already uploaded to the website here. And you can see, this is a screenshot of the TARGET Center website in order for you to identify those resources. And then here is just some other IHIP resources that are available currently on the site. And again, they include manuals and curricula, the pocket guides and other reports and resources that have been developed over the years through the SPNS program.

So without further delay, I would like to turn things over to Dr. Anne Rhodes, again, from the Virginia Department of Health, who will discuss their active referral intervention. Dr. Rhodes.

DR. ANNE RHODES: Thanks. Good afternoon, everybody. I'm going to talk today about our SPNS systems linkages grant and one of the interventions that we implemented under that grant. You just heard a little bit about that the SPNS program Special Projects of National Significance and so I'll just give a little bit of background on our SPNS systems linkages grant which was a grant
that we got in 2011. And it was a four-year grant. So it was really right after the National HIV/AIDS strategy came out in 2010 and there were five other states that were funded with us, North Carolina, Massachusetts, Louisiana, New York, and Wisconsin. And there's also an evaluation center at University of California at San Francisco.

And so really it was funding state health departments to really look at their systems of care and really how they could do some interventions to really work along the HIV continuum of care and work on linkage, retention, viral suppression. So one of the things when we put-- here in Virginia when we put our initial application together, we are really just starting to look across the HIV continuum of care and figuring out how to measure some of the things on that continuum of care.

And so we actually implemented four interventions under the Systems Linkages grant, and two of them were state wide interventions, one of them being this active referral grant and intervention. And so with active referral, we really were thinking about how we get people who are newly diagnosed or potentially who are reengaging in care how we get them linked to HIV medical care.

And one of the things that we looked at was that we didn't really have a standard process for making sure that that occurred and for ensuring that people got to their initial medical appointment. So we really decided that we needed to develop some standard tools and processes for making sure that people got linkage to medical care and ensuring that that linkage to care happened. So that's really what the active referral piece was about.

So we started talking about how to do that and how to really get that piece done. Part of the SPNS System Linkage's model was using what was called the learning collaborative model to develop your interventions. And so the learning collaborative was really bringing people together to develop the intervention. It was a tool that's been used in quality improvement processes before, but was used in SPNS systems linkages to really get people to develop the actual interventions in the first year of the grant and figure out the best way to develop those interventions and test them out.

As we developed this active referral intervention, we used that learning collaborative process to bring together a group of people to develop the interventions and to test it out. And so we really thought about what people we needed to have involved in this initial strategy group. And we really thought about our DIS, our Disease Intervention Specialists, who are really the people who sometimes are doing the testing, but usually also get the initial referral to go out to interviews and partner notifications, patient navigators, who are really-- that was another one of our interventions that we developed under SPNS Systems Linkages with a patient navigation protocol that we tested out in two regions of our state. And we were also doing other patient navigation type programs across the state and some community health worker programs as well that we were developing.
And so we brought those groups together, along with some of our HIV testing community-based organizations to work on developing this protocol for active referral. And they really hammered out what is an active referral. How are we going to track that? How are we going to make sure that the process-- how does the process happen? And tested it out. And we used that plan, do, study, act cycle that's brought in quality improvement to see if the process that we had for active referral would work.

And so we came up with this definition that's on the slide for an active referral, which is a direct referral to a patient navigator or medical provider. We didn't have patient navigation in all areas of our state at the time that we developed this. We still have probably a few areas of the state where there's not patient navigation services, making sure that there's documentation of scheduled medical appointments, and confirmation that the medical appointment was attended.

And so in order to really do that, what we've developed was this Coordination of Care and Services Agreement form, or what we call the CCSA. And so that form really took a while to hammer out and get a final form of it. I wouldn't even say-- we still will probably come up with new iterations of that form today. So I don't know that I can say we have a final form of it, because I'll talk a little bit later about how we have developed and adapted the form for some other areas of our program. But the CCSA form is really sort of the centerpiece of the active referral intervention. And I'll talk a little more about specifically what's on that form in a minute.

So this is a flow chart of the active referral process. So a client tests positive for HIV, we really initially were focusing on newly diagnoses persons but I think, as most people know, a lot of times people will test for HIV as a way to get reengaged in care. So there's a lot of previously diagnosed people who come through health departments or CBOs and get tested as a way to reengage in care. So we really do find a lot of people who were previously diagnosed.

So then there's follow up by DIS, to get them engaged in care, to do interviews and get them referred. And so at that time, the DIS, who are really who we initially focused on, although we did expand this to our other testing sites as well to community based organizations after the initial active referral development. So they determine if there's patient navigation services available in the area where the DIS is working, then they offer patient navigation services to a client. If there's not, they refer them directly to the closest medical provider who's providing care for HIV clients. And they use that CCSA form to refer the client to either patient navigation or a medical provider.

And I'll talk about specifically what's on that form. But that form goes through services that can be provided by the patient navigator or the medical provider. And also, the client provides consent for follow up for a period of up to two years so that they can continue to be provided patient navigation services and follow up for a period of up to years. So they make the patient navigator or the medical provider a rule to make an appointment. And they will fill out the
second part of the CCSA form and send it back to the DIS after they've confirmed that his attendance at the medical appointment within 30 days of the referral.

So they will make the appointment, confirm that the client came in for the appointment, and then they fax back the full form to the DIS or the CBO who make the initial referral to them. So there's a feedback loop, because that's one of the things we heard in the initial development of the process, was that DIS or CBOs may make a referral for care and then they never know if a person actually makes it to care and what happens after that process. So the CCSA form helped us to close that loop during that process. And so then the DIS gets the form back, and then they send the form in to us at the health department central office. And then we track the form here and I'll talk a little bit about what we've seen as some of our outcomes in a minute.

So the CCSA form really allows the client and the agency that's providing linkage services, they can see, there's a number of different types of services listed on the form - and I can share the form if anyone who wants to see it. It's a two-page form. And then it's got sort of a page of instructions as well with it. So while it has different types of support services and other services that the patient navigator can review, or the medical provider can review, or the client could view other types of referrals as well. So if they need housing or they need other types of support services, they can also use that form to refer the client out to other providers as well. And then the client signs it. So it's providing consent to help coordinate the services and also allows them to close that referral with the initial DIS or tester who referred them to care in the first place.

So we implemented that. We did some testing of the form. We did some tweaking of the form over time. And then we list -- our main outcome for active referral, we're really looking at linkage over time to see how long it was taking people to get linked to care after their initial HIV diagnosis.

Then a secondary outcome is retention and care over 12 months and 24 months. Those are really what we wanted to see, hopefully see improvements over time. And when we launched the active referral, and eventually we launched it statewide with all our DIS, we have between 30 and 40 DIS statewide. And then also once it was with our CBOs who do testing, but we focused initially really on the DIS as the implementers.

So we looked at our linkage rate, so here's our linkage rate in 2012, before we implemented active referral. And then in 2014, after we had implemented-- and we do from different populations-- I think across the board we definitely see increases in linkage rates. Now, you know, I think there's a lot of other things that were also going on at this time to increase linkage rates across the board, so we know it's not all just due to active referral, it’s due to the loss of different things, especially I think there was an increased focus on increasing linkage to care.

And these are all 90-day linkage rates at this point. I think we were starting to look at 30-day linkage rates, but at this point in 2014, we were still looking at linkage within 90 days of HIV
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diagnosis. So we know we could see some improvements. It's a little hard to attribute everything to the active referral piece. But I think we definitely saw some improvement.

We're still waiting to look at retention outcomes because those take a little bit longer to look at 12 and 24 months. So we didn't have that data. I think towards the end of this year we'll have some 2015 and 2016 retention rates that we can start looking at for those people who were engaged in care in 2014.

We had some challenges as we implemented the active referral intervention, our DIS, our statewide, we don't have a completely centralized structure here in Virginia. So some of our DIS are employed by the central office here and them some are employed by their local health department. And so the implementation varied I would say by health department so we had some DIS who were great at doing it and some who weren't always so great at always remembering to fill out the form and get them back to us. And the quality of the forms varied and we had to do a lot of back and forth initially and making sure that all the data was complete so that we could track outcomes over time.

We have a lot of staff turnover with DIS and some with the patient navigation personnel as well. And then just changes in HIV testing technologies and some of the processes for how we do linkage to care. So more quickly, just trying to get people more quickly linked to care, some of the ways that patient navigation and community health workers were structured in the state have changed over time. And so all of that, I think affected trying to get active referral implemented quickly.

But I think one of the other things that is a little bit of a change, I think DIS were always referring people for care. But I think, really just making it a process and another form for them to fill out was a little bit challenging at times. And so just trying to get it incorporated into their daily processes took some time. I think it has been incorporated pretty well now into their processes. But it was a new thing I think that people weren't always ready for.

Some of the successes of active referral, we've definitely seen increases in linkage rate. The collaboration piece, which I think across the board with SPNS system linkages has really been very helpful in lots of areas. So we developed patient navigation as another one of our interventions under systems linkages and patient navigators and the DIS really collaborated on developing this intervention and they were having routine monthly calls as they developed this piece. And I think that collaboration really helped with -just that they all knew who each other were.

We had a lot of new patient navigators who came on board with this project. And I think it really helped them sort of develop those relationships just because they were developing the intervention together. And those relationships have sustained over time and that's been one of the nice successes of the project. People know each other. It's much easier for them to work together, refer clients, and use each other as resources over time.
And even here within the health department, I think we've seen a lot more integration across all of our HIV programs, the prevention care and surveillance. I think we all have worked together a lot more as a result of SPNS systems linkages and some of the other projects that we've had that have really worked to integrate all of these pieces to work across the care continuum. So that's really helped I think. Especially with active referral I think we've been doing a lot of work with our field services unit here at the health department who oversee and provide guidance to the DIS. A lot of times they're working on syphilis, gonorrhea, and chlamydia, those pieces and they're working on HIV, but sometimes they're sometimes a little bit separate but this active referral piece really made us all work together more, and I think has really helped with collaboration across programs.

So some of our future directions for active referral. One of the things is we started our data to care program three years ago. And the CCSA form has really been an integral part of our data to care. So when we were developing data to care, just really working with our community-based organizations and medical sites to send them lists of people who were completely out of care and have them reengage people, we looked at the CCSA form and we were like, this is a pretty good form to use for that as well.

So we used that CCSA form and we just added another page to it for data to care, which basically asked them to report on dispositions of clients that they are trying to reengage in care and if they found someone who was out of care or if they're already in care, and they report a few other things on that last page of the form. But they really use that CCSA as sort of a base so it really helps sort of jump start our data to care effort as well.

The active referral piece is also being used now for hepatitis C. They're starting to use it to make referrals as people are diagnosed with hepatitis C. They use it sort of in the same way as it's being used for HIV if people were referred to medical care and confirm appointments. Active referral has been used as ongoing training for the DIS, and they're putting that piece of it, the expertise for active referral, into job descriptions for DIS and expectations. They developed a field operations manual for DIS and active referral as part of that operations manual.

And then we've also started funding some DIS positions that are specifically dedicated to linkage and re-engagement services. We rewrote our Ryan White Part B supplemental grant this year and got some funding for some specific positions that are DIS positions that will be located in local health departments but will be specifically dedicated to doing linkage and re-engagement work.

And then just final key points here, which I probably have hit most of already, I think, doing this linkage to care, I think as we worked on it, we really found that it really wasn't as straightforward as we initially thought it was going to be. I think we thought, you can fill out this form, get people referred to care, confirm their medical appointment, and I think the DIS and other linkage personnel really found that a lot of times people-- one of the things that we
found I think, was that people were not always ready as soon as they were diagnosed to just immediately be linked to care.

And we still get a number of forms back where people have sort of refused services initially because they may not quite be ready initially for that linkage to care piece. And I think that’s something we still are thinking about. They may have other barriers, that they're not quite ready. So I think we still have to think about that.

It was a little bit of a shift for some of our DIS initially to really focus on the linkage to care. Some of them were a little bit more focused initially on other pieces of job, partner notification, those kind of pieces. But I think that occurred kind of across the board. I think we've realized that there's the need for ongoing training across the board, not just with DIS, but with the linkage for the patient navigators and others, that there's a lot of turnover, and there's updating of resources and things that need to happen so that it's not just kind of a one and done. We need to constantly be training and working with people to make sure the forms and the processes are meeting the needs of people.

And then we are actually working on enacting this process also as we're launching our PrEP program statewide. They're working on using the CCSA form to do linkages for people to do PrEP as well. And I just want to say thank you to-- we had great HRSA staff that worked with us on the SPNS linkages grants, everyone here at VDH. And then Lori DeLorenzo who was our coach and who helped us really with our learning collaborative model. Thank you.

SHELLY KOWALCZYK: Alright. Thank you, Dr. Rhodes. So, I would like to turn things over now to Val Robb at the UCSF HIV/AIDS Clinic at San Francisco General Hospital to talk about their viral hepatitis program. Val.

VAL ROBB: Hi. All right. Let me get the slides up and I'll begin. I wanted to talk today about the hepatitis C treatment and expansion initiatives that we participated in from 2010 to 2012. We were part of a 15 site collaborative as the first round of that expansion initiative. And we'll be presenting about the background of our clinic, how this grant allowed us to build capacity and team, some of the lessons that we've learned, and a bit about, in this dynamic environment of hepatitis C treatments, where we've gone since 2012, with the recommendations for other sites.

We are based in San Francisco. We're a UCSF clinic that's based at the local public health hospital, with a rich tradition of providing HIV care. We were at least one of the first clinics in the country to start providing a dedicated clinic for HIV. We have approximately 2,600 HIV patients. And when we began really focusing on the hepatitis co-infected population, we estimated we had about 30% of those patients were co-infected.

We began a robust and aggressive initiative in 2004 in the age of really challenging treatment with a success rate of about anywhere from 30% to 50%. We began aggressively teaching, identifying, and treating our co-infected patients in an effort to really prevent death due do
hepatitis disease. We had kind of what we called a boutique approach, which was that there was one champion, our medical director, Dr. Brad Hare and myself, who really were the program.

We were the consultants for our more than 20 or 30 different providers to evaluate their patients and then monitor them closely during treatment. And then early on, we adopted a model that was suggested by mentors, Dr. Diana Sylvestre in Oakland at the Oasis Clinic and Dr. Lynn Taylor on the East Coast, who really supported the concept of weekly education and support group. And we began that in 2004.

By the time we applied for the SPNS grant, we really felt that we needed to transform our model. And in a word, we needed a there-there. We were no longer satisfied with not having a dedicated Hep C clinic. And the SPNS initiative really allowed us to fund twice a month Hep C coinfection clinic that was based at our current location. And in developing a clinic, it really allowed us to solidify relationships that we had with our on-site psychiatrist and one of our on-site social workers to provide team care in that way.

The other things that in building this capacity, the other thing that we wanted to do was to set up an interdisciplinary team meeting that occurred right before each clinic. Prior to that, I was really the screener, the sort of the one stop shop that would talk to the provider or the patient, send the report to my medical director who would say let's proceed or not proceed, and then we would get the medicines ordered and start them on treatment. But we had no place really, and no timeline, to sit down and meet with patients or for our medical director or to actually sit down as a hepatitis specialist and meet with the patient directly.

This is a big change in our practice and we're really excited about it. We maintained that we had a twice a month clinic on Tuesday afternoon and we maintained the weekly Hep C support group that happened at the end of clinic. So it increased our sort of one stop shop model with sort of there-there approach so that we could sort of maximize our time and the patient's time.

We had some great outcomes from this two-year process, and again, during that time we participated in monthly calls with the other sites. We had access to technical assistance from our HRSA SPNS colleagues, and again, it allowed us to increase our cross training in our interdisciplinary team. Specifically, in interferon age -we really benefited from having a psychiatrist specialist and a social worker who was really adept at working with people with mental health, substance abuse issues, who are a lot of our Hep C co-infected patients.

So lessons learned. Overall, we found, even though we were only treating-- now I can say only, but at that time we were happy with treating 10 to 15 people per year. We increased that by about 45% more treatments per year. We also felt that by scheduling people in our clinic, we were able to treat people who would not have been able to make it through the treatment trials that were going on at that time. By having a scheduled time, and people didn't show up or repeatedly didn't show up, we were able to help the provider and the patient clarify their dread or ambivalence about starting an interferon based program. And conversely, we were able to
help people get into the clinical trials by doing the education and the teaching through clinic, and then helping people refer to clinical trials.

I've spoken already about the clinical case conferencing that we did. And again, as the treatments have changed, we are able to focus more on ARV regiment selection and education around that. And then using the sort of support of the clinicians to figure out adherence issues. And again, it may go without saying, that by being an HIV clinic we found that if patient had HIV well controlled, that that was a good sign that they at least had some basics down of adherence. So we may have had an advantage in that way over our mono infected patients and the colleagues treating them.

Our Hep C patient support group remain a key component of our program. By this point it had a really rich history and had been going for a number of years. And as we saw treatments changing, we saw that we were able to focus not only on the basics of Hep C, what's your viral load and your genotype and what is it to find out how your liver is doing, but as clinical trials and new treatments emerged, we had the experience that people came to our support group and were themselves on those new regimens and were able to educate other people in the group about side effects, and responses and stuff. So it remained a backbone for many, many years.

As the SPNS grant support was winding up, we were able to sustain, through really the dedication I think of our clinic leadership, we were able to sustain our twice a month clinic model, which is still going on now, although it’s again in another transition, which I'll talk about in a little bit. But we subsequently obtained a grant through Vertex, which has allowed us to expand our model within the San Francisco County and it was a one-year expansion grant. We were able to mentor several other sites, a community methadone clinic, another primary health clinic, and Laguna Honda, which is basically the city's nursing home and rehab facility that has a dedicated HIV unit.

And we were able to expand our model that included both the support group, we trained peer educators and provided a network for supporting treaters at all of those different sites to be able to educate and treat people. I'm showing here on the slide, we developed-- it came from an idea from our peer educator -my info card, which allowed patients to write down their info, were they positive for the Hep C antibody? What was their viral load? What was their genotype and had they had any imaging or pictures done of their liver? And it kind of gave us the opportunity to see if our model, --how it succeeded at other sites.

And it was quite a moving experience. At the methadone clinic, for instance, we found that many of the patients there, or the participant, knew that they were antibody positive, and many, many people thought that they might have terrible Hep C. And yet when we finally did the Hep C viral load, they were the one out of four or one out of five lucky ones that found out that they didn't actually have Hep C. And as we continued with the group, more and more people came and some of them got that lucky news. Others were reported to go on to treatment and seek a cure.
At the rehab and nursing facility we had a lot of people with mental illness and traumatic brain injury, some dementia, and it was quite a profound experience to see people with some decreased capacity able to take in the basic information about hepatitis and support each other through treatment. We were quite moved by it. And both of those remain successful in educating and treating their patients. Our grant was only for one year. And so we supported them from that and then have remained in a network but have backed off of the active mentoring process.

I think it’s really important to try-- it was actually helpful for me to try to identify what were the keys to the sustainability of the SPNS grant beyond the initial two years. And really, the first thing has been that the clinic leadership in our clinic has been absolutely committed to continuing this effort, and that the core hepatitis team, which is really now has been Dr. Hare initially, and now Dr. Annie Luetkemeyer, myself, and then we have a pharmacist now that’s come on the team, our social worker, and less and less, our psychiatrist. But the core team has remained incredibly dedicated, despite fluctuations in funding.

As well as all that education that we did over that decade it’s meant that our patients, even the ones that avoided the hardships of the interferon era treatments, knew what they wanted and knew what they were waiting for. So we’ve continued to have a treatment demand by both the providers and the patients, who are waiting for these newer treatments that came out. We’ve had ongoing funding from little pots of money here and there. But a little, I empathize a little, and intermittent.

But again, I’ve been able to keep going. And really the key to sustainability I think, in this program has been the advent of better treatments. And I'll talk a little bit more about that later. Again, I think our challenge has been sort of just the lack of dedicated Hep C funding. And I think the issue with that has just been again, I think this is not just a local or a local site issue. I think it has been an ongoing struggle for all of us in the HIV community and again in the larger community around developing Hep C activism and dedicated funding streams.

So I mentioned this earlier, I wanted to go back again to these two years where we really increased our capacity by providing a dedicated clinic. We found that we actually had lower rates of treatment discontinuation when we went from that sort of boutique, embedded model into a dedicated clinic with regularly scheduled follow ups. We had similar high rates of SVR and I didn't list them here because --I don't know, I just didn't list them.

But we did OK in sort of having treatment successes, that paralleled really study levels on interferon and ribavirin. And at the very end of the SPNS grant, saw new treatments emerging, which again, was increasing our success. We overall felt that the monitoring between initial evaluation and treatment initiation was shorter and the follow up was able to be more organized, and that really that this having had there-there, having a team meeting twice a month, allowed for efficient communication, improvement in morale and energy, and you know, overall I think, efficiency and improvement in care.
During the time of the SPNS grant, I think that we in retrospect, looking back now through my lens of today, I think that we would have even had higher rates of treatment, but we had new drugs being approved at that time and there were lags in insurance approvals. We had a group of people that was really wanting to participate in one of the clinical trials and the clinical trial got delayed. So there was a whole group waiting to start treatment. And they kept being postponed.

There was always a core group of patients that were never going to take interferon. Either they couldn't or they wouldn't. And they knew that better treatments were coming and they thought that they had time to wait. Most of them did. And then for many, these challenging treatments were just never going to be possible. So what we did to overcome the barriers, I think was to continue with our advocacy, both within the clinic and within the larger community, to maintain our patient support and education. And really ultimately the better regimens that came along have really transformed our model yet again. And I want to talk a bit about that in the time that I have remaining.

This slide, I might have found for a training several years ago. And I can remember looking at the block at the top, which said easy dosing once daily, low pill burden, and thinking, oh my gosh, I can’t wait for that time to be here. And it seemed so far away. And now it’s here. And I have chased people for a decade, wanting them to get Hep C treatment.

And there were some people who couldn't wait, but many, many people did not have advanced liver disease when we first looked at them, and they elected to wait. And so now what we have is not just one, but several options for a one pill, once a day, with minimal side effects, in generally a three-month treatment window. And again, this ideal Hep C regimen again, which is still I think improving monthly or at least quarterly, has really changed how we are delivering care in our clinic.

So just to review, in 2011, there were two drugs approved, telaprevir and boceprevir, they were the breakthrough drugs, oral regimens and they still were used with a drug, interferon, which is an injectable that causes depression and rage and fatigue and flu-like symptoms, and then ribavirin, which causes anemia. In 2015, the breakthrough combo pill, HARVONI, was finally approved and then since then, we've seen a couple other pan-genotypic, which means it treats all kind of Hep C medications approved. So this is really quite a thrilling era for us.

We went from treating about 10 people a year to treating maybe 20 people a year, to last year, we treated 75 and this year our goal is to treat 100 patients. So the challenges of that and the opportunities are very, very different than they were even a couple years ago. What we have seen for that is that it involves changing our team composition.

So we used to have a psychiatrist to help us manage all the side effects from interferon. We no longer really consider the psychiatrist as a core team member. There are not psychiatric side effects from the newer medicines. What we instead have needed is a pharmacist, because there are some significant drug-drug interactions with some of the medications that people
routinely use. And we have also, given that we have increased our treatment volume exponentially, have really counted on our expert clinic pharmacist to really streamline the prior authorization process and also be an advocate.

So that's been one of our-- for those of you who are in the process of adapting your models or launching models, this has, I think, been a key change for us. And again, we are really trying to-- it's been a learning curve, I think for myself, I feel like an aging nurse trying to adapt from a model where it was really intensive nursing. Supports for treatment starts would take an hour of education, and weekly phone calls. It's now handing somebody a bottle of pills and saying, you probably won't have any side effects, there are a few, remember to take them, and if you're hospitalized or jailed or something call us so you don't miss a dose. And come get a lab draw once or twice during the three months. It's really required a sort of a paradigm shift for me. And a way to sort of monitor and track people differently.

Our clinic prioritized getting all of our cirrhotic patients treated first. And I'm happy to say, I'm not 100% confident, but I think we are closing in on our last two or three known cirrhotic patients, those with advanced liver disease. We're closing in on getting them treatment. We have one woman, cirrhotic, who is about to start treatment a month from now; and the other person who'd been really reluctant, for a whole lot of complicated mental health reasons, has been reluctant to start the medicine, even though we have a drug available for him. Does it mean we won't get new cirrhotics coming to our clinic or that we have people who are sort of loosely engaged in care out there that we want to find and treat? But essentially our goal is that we do not lose any more patients to hepatitis C related death.

In the early years, we were working on getting people transplanted. And I'm happy to say we had several patients who successfully obtained a new liver with a lot of intense support. And we're really hoping that we see the need for transplant and to avoid any kind of advanced liver failure from hepatitis C. As I've mentioned earlier, we now pay a lot more attention to our ARV regimen and drug-drug interactions and that starts right at the beginning and it's been a paradigm shift. And as we've understood the recommendations, we've tried to spread the word. But again, this is a very dynamic time for Hep C treatment and so the paradigm that I've learned as a nurse around even what HIV meds to recommend to providers, change almost overnight it feels.

And then the other kind of-- as a nurse I work a lot of translating between patients and other disciplines and trying to interpret messages into little bite-size points. And I think that what we've seen is that if our patients can take an HIV pill, they can get cured of hepatitis. Now unfortunately we're down to the cohort of patients that really is struggling both with HIV and Hep C. And I think that's a way that we're changing in that we're trying to identify now how to help those patients overall. And it's possible that our model will switch back to again counting much more on the social worker, the substance abuse counselor, and the psychiatrist to help us get to that goal. We'll have to see.
Now that we have our dedicated clinic, our ongoing capacity building has changed so that we have an attending physician, Dr. Luetkemeyer, who now trains two of our infectious disease fellows to help in clinic. We trained two last year and we're just starting with a new group who's going to be rotating through clinic this year. We are switching to being able to not just have patients come to clinic, but have the option of the provider asking for a quote unquote electronic review of the patients. So we're, in some ways going back to the original model where we can consult with the expert and then treat the patient with some infrastructure monitoring, without them having to come to the dedicated clinic.

As somewhat of an outgrowth of the original expansion model, there is a city-wide network of Hep C treaters and we've been able to put some systems in place so that providers in all the community sites within San Francisco can send in for a consultation or get somebody seen. We have again, maintained coordination with our clinical trials group. So we have a clinic on one floor and the clinical trials group is on another floor. There's also an offsite clinical trial group that has helped to treat some of our patients over the last few years.

We continue to look for and cull our electronic medical record and that involves doing a twice a year data review to make sure that we're not missing any patients. And then we send the list to each provider, also team-based clinics and to the nurse for the teams. And we're potentially changing our model so that instead of asking the providers to say, who do you want us to treat, we're thinking to change it to say, tell us who you don't want us to treat. And then we're going to look at trying to treat everyone else. So we'll see how that goes.

We have a roadmap for eliminating Hep C in our clinic. So we think probably at the time of the SPNS grant, we had about 450 to 600 patients who were Hep C, RNA positive. About probably, at best, 360 of those were treatment candidates, and we treated a small group of them a year when the interferon based regimens were what was available. We started to, as the newer treatments came available, we wanted to have the goal of treating 50 to 100 per year, which would mean that we had a goal of eliminating hepatitis C coinfection in our clinic in a four-year timeline.

Now you will notice that the 100 or so or 200 or so that really can't take a pill, is not who we have figured out a way exactly to move through, except to say that we have seen people who were unstably housed and deeply involved in drug use with the motivation to get their Hep C cured and intensive case management, be able to stabilize and then get treatment. And we're actually treating a couple people who started treatment and then decided-- they didn't really decide, who then unfortunately, had to visit either the county jail system or the statewide jail system, were able to continue their treatment during that time.

So at my most recent count of our database, and again, I run this list twice a year, it looks like we may have, including the people that are unstable, only less than 200 people left to cure in our clinic. So we're very, very excited about that goal. And as I said I think we've zeroed in on the cirrhotics and we really are closing in on them, and I can talk more about how we evaluate the cirrhotics if people are interested.
So I think that's the overview of what I had. I wanted to again thank our SPNS team for their support, ongoing support, and this opportunity to present what we learned. I'd like to thank Jessica Xavier who was our support during the SPNS thing and my technical assistant's mentor. And thank you again for the opportunity to present.

SHELLY KOWALCZYK: Great. Thank you so much, Val. Thank you both, Val and Anne. Those were great presentations and a lot of useful information. We appreciate it. Quickly here, before we do open up the lines for Q&A for both the presenters, I did want to mention a couple things. So our last webinar in the series is September 19th at 2:00. And it will be the same link and number. And I also wanted to bring up how to-- I'd mentioned staying connected.

If you have any questions following this webinar or any time, you can submit it to IHIPHelpDesk@MayaTech.com. We also have a dedicated Listserv to receive the latest news and announcements about products and webinars. And as Sarah had mentioned in the chat feature, if you guys saw, for those that were interested in copies of this slide presentation, -- if you sign up for the Listserv, you'll receive an announcement about that, when those are available on the target site. And then lastly, again, is a URL for the TARGET Center website.

So operator, we can go ahead and open it up for any questions that folks have. I see there is a question in the chat feature. Do the DIS positions dedicated to linkage and re-engagement require any special training?

DR. ANNE RHODES: This is Anne. So, for the linkage re-engagement, we do have some training that we put together for the active referral piece. We did regional training. We had five health regions. So we did go out and do-- there is training that they all go through for the active referral piece, which is really specific to how to an active referral, how to fill out the forms, the resources that are available. We did it regionally because there are different resources available in different parts of the state. They have a resource directory on patient navigation and medical resources and other resources that are available specifically in their part of the state.

So, yeah, you do go through special training. It's all outlined in the manual, that I think Sarah talked about earlier. They're coming out through the IHIP and I'm glad to share information with it. DIS go through their regular training as well as passport training that CDC offers. But then they do go through a special training and then we do have, at least every six months there is refresher training --there's monthly DIS webinars that we have here at the central office that over different DIS topics. And we get a piece, at least twice a year, where we do a refresher training on those webinars on the active referral protocols for all the DIS so that we can sort of update some things for them to kind of remind them of all the different things that need to happen.

SHELLY KOWALCZYK: Thank you.

TELEPHONE OPERATOR: Miss, we've had no further responses from the phones.
SHELLY KOWALCZYK: Thank you. Anne, I did actually have another question for you. In thinking through with so many organizations having oftentimes multiple grants and various data requirements and procedures and entering information in EHRs was there any pushback to trying to implement this particular process?

DR. ANNE RHODES: So yes, I would say, there was a little bit of pushback, from DIS especially have a lot of paperwork that they do. At our local health departments, I don't know how every state or jurisdiction is, but I know here in Virginia, our DIS, they have a lot they're doing, interview records, field records. There a lot of paperwork. We don't actually-- as a state health department, we don't even have really-- there is an electronic system division that is used in our local health departments to report encounters, but there's not really a local electronic medical record at all the local health departments. So there's still really a lot of paper based pieces. So that is one of the—we did get a little bit of pushback on sort of adding another piece to their workload.

One of the things I didn't mention I think, is that we have-- we actually recently-- we have another SPNS grant, which is a health information technology grant. And we didn't-- one of the things, we moved to a new data system for Ryan White and HIV prevention, which is web based. And part of that new system actually has-- most of that CCSA form is electronic in the system, in the new system used in Virginia now. And so, pieces of it can be done electronically. And we are working towards making it a little more electronic.

There was definitely a little bit of pushback, but I think there was also, people started to see the value of getting that feedback. And clients really like being able to get linked to the services, know where they were going, get that sort of immediate linkage to patient navigation or medical care. And I think as it's just been more-- the longer it's been in place, the more it's been sort of worked into regular practice. That's the last pushback we've gotten.

SHELLY KOWALCZYK: Thank you very much. Val, I actually had a quick question for you as well. You had mentioned something that stuck in my head when you were talking, I saw the bullet around insurance approval delays. And I was wondering, especially with this changing landscape and hepatitis C treatments, you know, how much of a barrier is the insurance process and did it actually dissuade some clients that you know? Or have you been working with a pharmacist or someone who is very knowledgeable and stays up to date so it's been perhaps an easier process for you guys?

VALERIE ROBB: I think that for us, we had initially, with the first breakthrough in oral medicines, we had some big delays. And then we had some initial delays with the approval of the first interferon free regimen. And then there's been a lot of advocacy in California, so that as soon as the California Department of Health made the recommendation that people with HIV should be treated, regardless of their status, and you know, regardless of how much liver disease they had, it really changed the landscape for us. And we have some of the regimens available on our ADAP formulary, which we try very hard to avoid.
And so we have been very, very lucky. We have one patient now-- initially we used a lot of patient assistance programs through the pharmacies, and as those dried up, luckily the insurers, most of our patients actually are Medical. We don't have a lot of privately insured patients. Now I don't think we have any. So we have one patient now that had to go through a patient assistance program. So we've been very fortunate and we snagged the fabulous pharmacist from the community, who is very assertive and skilled at that as well.

So I know, I hear from our colleagues in other areas that there has been lags from insurance, but we've been really fortunate here.

Again, thank you. Brad, were there any other questions from the audience.

TELEPHONE OPERATOR: We've had no further questions from the phone lines at this time, Miss.

SHELLY KOWALCZYK: All right. Well, I don't see any others in the chat feature either. So just lastly here, before you depart, if you could please use the link that's on the screen right now to complete a very brief survey to get some feedback on today's webinar. We would greatly appreciate it. And then again, within the next few weeks, both the slide decks and the archived webinar recording will be available on the target center website. So guests who send an email to iHipHelpDesk@mayatech.com or you can sign up for the Listserv as well to get information about that. So thank you so much for your participation. And again, if you have any additional questions, don't hesitate to ask.