**Addressing Systemic Racism and Disparities in Genetic Testing**

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**Altovise Ewing:**

We have to get over this idea that underrepresented and underserved populations are not interested in

participating in research. Basically, we have to stop conducting convenient science.

**Deepti Babu:**

Hi, everyone. Welcome to our next episode of the Genetic Counselors and You podcast. To say the

coronavirus pandemic is impacting all of us, is an understatement, but it's also exposing disparities and

social inequities embedded within healthcare.

**Deepti Babu:**

For some of us, it's the first time we've talked about social justice or systemic racism. For others, we've

felt their effects for some time. But did you know that racial and social inequities also exist in genetic

testing? In this episode, we talk with a scientist, who is also a genetic counselor about systemic racism

and other health disparities rooted within the genetic testing experience.

**Deepti Babu:**

We aim to shine light on these issues and call out ways that genetic testing developers, marketers, and

medical professionals can work to dismantle these inequities. So today we're talking with Dr. Altovise

Ewing, Senior Science Leader at Genentech. She's also an incoming director at large, on the board of

directors for the National Society of Genetic Counselors.

**Deepti Babu:**

Altovise is a genomic health equity scientist, and genetic counselor. Her work focuses on centering the

experiences of diverse groups in genetics, genomics, and bio-banking research, including addressing

ethical, legal, and social implications. Welcome Altovise, and thank you for joining us today.

Altovise Ewing:

Thank you so much for having me, Deepti. I'm really excited to be here today.

**Deepti Babu:**

I am thrilled to be able to talk with you for a number of reasons, but I mean, you have such a rich

background with your training in genetics, genetic counseling, health disparities, and just your life

experience. What is it that actually made you want to pursue your current work right now?

**Altovise Ewing:**

Yeah. Had you asked me 13 years ago, if I would have imagined myself in a role such as this, the answer

would have been no. Because at that time, this role did not exist. So I would say, I've always been

driven. I've always been centered on health equity, eliminating health disparities and making sure the

voices and the needs of underrepresented and underserved populations were a primary focus or were

not forgotten.

**Altovise Ewing:**

So I really think my role at Genentech as a Health Equity Scientist is a phenomenal marriage of that

passion for genetics, advancing inclusive research, and really advocating for underrepresented and

underserved populations. It's landed me in this phenomenal role. And I could not have asked to be in a

better place.

**Deepti Babu:**

How wonderful that you can combine those things into your actual job.

**Altovise Ewing:**

Yep, absolutely. And it wasn't easy getting here for sure. I can recall throughout my journey, there were

definitely moments where I felt discouraged, where I was even dissuaded from pursuing health equity

and health disparities work. But I always felt like it was the right thing to do. And even though neatly

created positions were not available at the time, I always felt as though if I followed my passion and if I

continued to do the right thing, then doors would open and those opportunities to be of greater service

would definitely ensue.

**Deepti Babu:**

I think being part of an underrepresented group in the field of genetic counseling, I can say, I'm guessing

that that was a big factor for you, having lived that experience yourself. And that's one of the things that

I wanted to talk about today in the context of genetic testing. So there's the underrepresented groups

within our field, which are, you could certainly speak to those. But then there's the underrepresented

groups that are actually representative of the genetic testing experience. Do you see those as related to

each other?

**Altovise Ewing:**

I would say they're absolutely related. Even when I reflect on what motivated me to become a genetic

counselor, I recall sitting in my senior genetics course, my senior year of college and just really going

over some of the advancements, as it pertains to the sequencing of the human genome.

**Altovise Ewing:**

And also, learning every single day about some of the disparities that existed between black and white

women in terms of health outcomes, as it pertains to breast cancer. And I really saw genetic counseling

and genetic testing as a tool to really help level the playing field, in terms of affording equitable health

outcomes for all women, regardless of race.

**Altovise Ewing**:

For me, it was really that love for family health history, and being able to talk about your family health

history, as well as your family history. And being able to bring that into a setting where you could talk to

a healthcare provider, such as a genetic counselor, to determine if one was eligible or an appropriate

candidate for genetic testing.

**Altovise Ewing:**

And then if so, I really saw it as an opportunity for individuals to make informed decisions and to

potentially access information that could help them navigate their medical management to help reduce

their risk, or even prevent the occurrence of a subsequent cancer, if they already had a diagnosis.

**Altovise Ewing:**

So I would definitely say being from an underrepresented population myself, and just knowing how

those cancer health disparities hit home, how, when I saw commercials or I read an article, I always saw

myself because the articles or the commercials were oftentimes about young women with breast

cancer. And even though I've never been diagnosed with cancer, I was just always devastated that it

oftentimes disproportionately impacted women who are young and that same group of women

oftentimes experienced worse health outcomes.

**Altovise Ewing:**

When we think about genetic testing today, and we think about who accesses the service and the tool,

we do still see a disparity or a difference between certain groups that do access and certain groups that

are not accessing the service for various reasons. Those reasons could be due to the lack of knowledge

or awareness about the services. And then oftentimes, it comes down to some of the healthcare biases

that exist as well, where certain groups are not even referred for genetic counseling and genetic testing.

**Deepti Babu:**

Right. I just want to take it back a little bit to when you first talked about some of the disparities that

you noticed specifically, if we just talk about women with breast cancer. And that's actually something I

don't think people realize, and certainly not when it comes to genetic testing, that perhaps there might

be disparities in that as well.

**Deepti Babu:**

So whether that be the testing, that is something that your healthcare provider is offering to you, or

maybe testing that you're considering doing at home, there's inherit disparities and some systems of

racism built into that genetic testing. And I wonder if you can talk a little bit about if you just use the

example of breast cancer, if that's something that you had noticed even earlier in your experience as a

genetic counselor or when you made the move to industry and began working in the genetic testing

space?

**Altovise Ewing:**

Indeed. And I can even take it back so far as to my genetic counseling training. So during my cancer

rotations, I made the observation that there were a number of young women who were diagnosed with

breast cancer, who met with us as genetic counselors, but unfortunately, they could not share sufficient

information about their family health history.

**Deepti Babu:**

Why wouldn't they be able to do that?

**Altovise Ewing:**

So, unfortunately, there are where someone may not be connected to both sides of their family. So they

may know more information about their maternal side of the family, but they may not know as much

about the paternal side of the family or vice versa. And unfortunately, during that time, some of the

women did not have information on both sides of the family. And there just was not sufficient

information to qualify them for genetic testing at the time.

**Altovise Ewing:**

And I just remember being so disturbed by that, because again, I looked at a number of these women

and I saw myself and I saw that they were being devastated by a disease, that they were not eligible to

access a resource that could have helped them tap into what was really precision and personalized

medicine at the time, and medical management that would have really personalized their screening

regiments, or even offered a particular type of surgery to them based on the genetic information that

we could have gleaned.

**Altovise Ewing:**

And in that moment, I went to the director of my program and I shared with him, my observations and I

shared how I thought this was contributing to the disparities, the chasm that we see between white

population and the black population, as it pertains to breast cancer and cancer health outcomes in

general. And I told my director that I wanted to be part of the solution, that I wanted to help tackle

cancer health disparities, that I wanted to really evaluate the problem, to see if I could post solutions to

help eliminate those disparities.

**Altovise Ewing:**

And that happened during my cancer rotation as a genetic counselor. And in that moment, I knew that I

wanted to be part of that scientific force that was really championing health equity and health

disparities at that time.

**Deepti Babu:**

Actively working towards the solution.

**Altovise Ewing:**

Absolutely. And then also ensuring that those individuals who were represented in the science, were

also those individuals who were going to be impacted in the clinic. Because the other thing that I

observed during that cancer rotation is that a number of women from underrepresented and minority

populations, who actually underwent genetic testing at the time, oftentimes received an inconclusive

result. So it may have been a result that was not as informative as it may have been for a woman who

identified as European descent or as white.

**Altovise Ewing:**

So that was more so a function of our limited knowledge of how genetics really impacted disease in

various underrepresented and underserved populations. And that's where I really wanted to highlight

and better understand, what are some of the barriers that minority populations experience when it

comes to getting involved in research and what are some of those motivators that encourage them to

get involved in research, so that ultimately we could optimize the utility of the advancements, of the

tests that are generated, so that they could be equitably beneficial for them as well.

**Deepti Babu:**

Right. Yeah. I mean, when you were talking about how the underrepresented groups that would go

through genetic testing had a higher, I guess, experience receiving these variant results. So just for the

audience, a variant of uncertain significance means there's a change that's been found in the gene, but

we don't know the meaning of it yet. And that's just our limitation of our scientific knowledge.

**Deepti Babu:**

And so when you say that, I wonder if people even really know that so much of the testing that we have

is, when we try to compare it against what we understand to be, "normal," that's often built off large

populations of often Caucasian, white, European background individuals. And that just depends on the

disease that we're talking about, but I don't think people who have genetic testing always realize that

your result may come back and it may be a bit more limited for people of your ethnic group, simply

because of our scientific knowledge. And I don't know how much that's really changed over the years.

**Altovise Ewing:**

Yeah. And unfortunately, it hasn't advanced at the same rate that the availability of tests have and it has

to change. It's really unacceptable at this point. And it's going to require an active effort of team science.

We really know how, when we collaborate and when we really buckle down, we know the amazing

advancements and achievements that that can ensue.

**Altovise Ewing:**

And unfortunately, that same effort has not been applied when it comes to ensuring that genetic testing

offers equitable benefit for all populations. However, I do remain hopeful. I think it's just going to

require us, as a scientific community, to get comfortable being uncomfortable. But at the same time, to

do something that we're very familiar with in terms of being innovative and thinking outside of the box

and working together.

**Altovise Ewing:**

Because various populations, underserved, underrepresented populations deserve to benefit just as

much as the majority population from these tools and resources. And it is going to require us to

oftentimes, put our personal benefit aside, put our respective company benefit aside and really do

what's best by these populations because these are populations that have been disproportionately

impacted for decades and centuries in some cases.

**Altovise Ewing:**

So we're at a point where we know that if we work together, we can make some significant

contributions and some substantial progress and it's really time for us to do so. I think we really owe

that to our patients, owe that to the various populations and communities.

**Deepti Babu:**

Yeah. I mean, I feel like there's a couple of prongs here. One, is the fact that the testing, let's just say, it's

not as good for certain ethnic groups as it is for others. So that needs to change for sure. And that's only

going to happen with advancing scientific knowledge and priorities, like you were saying, to shift such

that we actively put those higher up and they're harder to get to. And I think that's why they're easier to

ignore. You know what I mean?

**Altovise Ewing:**

Right.

**Deepti Babu:**

They're less common right now, but that will change as we learn about them and understand them.

That's one part. And then the other part is we have these very strict criteria for testing in some cases,

that repeatedly keep certain populations out of that opportunity. And that's what you were talking

about I think, when you go back and think about your genetic counseling training rotations. Even back

then, it was like, well, if you have X, Y, and Z, then you can get this test. I think that's shifting a little bit

now, but it's not great.

**Altovise Ewing:**

Yeah. We definitely still have a long ways to go, but I think you really hit the nail on the head when you

said that basically, we have to stop conducting convenient science. So we have to stop conducting

science with those populations who always self refer. There are scientists, there are pioneers out there

who have been working with underrepresented and underserved populations for decades, and they've

done so successfully.

**Altovise Ewing:**

And I think that they have done a phenomenal job of really generating some of those best practices and

strategies, in terms of successfully, ethically and respectfully engaging underrepresented and

underserved populations. So it can be done. We just have to go to those experts and partner with them

in order to do it in a manner that it translates into the genetic space as well.

**Altovise Ewing:**

And the other thing is, we have to get over this idea that underrepresented and underserved

populations are not interested in participating in research. Because as a trainee at Howard University,

the vast majority of people who engaged in research were overwhelmingly interested and oftentimes

because they wanted to do something that would help their family members in the future. They don't

want to see people going through the same type of experience as they've endured.

**Altovise Ewing:**

So, that interest is there. We have just got to find a way as a scientific and a clinical community to tap

into that interest and to do so in a way that we are proving to our patients that we are trustworthy and

we are truly there to be of service to them.

**Deepti Babu:**

Yeah, absolutely. I like what you said about stopping the practice of conducting science that's

convenient because I do think it is built upon, as we've had so many of these conversations more

recently, thanks to the pandemic that we're in, to do with racial justice and systemic racism. This is no

different from those, which is, we're just needing to change the things that we focus on because they've

always been that way. And that's going to take some work and that's going to take some discomfort, but

it's not until that happens, that we all begin to gain from that.

**Altovise Ewing:**

Absolutely. And it's going to require that we implement equity and that we take an equitable approach

in everything that we do. So even when it comes to reaching certain populations or ensuring that they're

able to access genetic counseling and genetic testing as resources, and even participating in research.

**Altovise Ewing:**

We do not take a one-size-fits-all approach when it comes to genetic counseling. And we can not take

that one-size-fits-all approach when it comes to engaging groups and research or ensuring that groups

benefit or even really understand the science and the technologies that are driving the field.

**Deepti Babu:**

Yeah. The aspect of, I guess, what folks might be listening to this episode, is how this impacts genetic

testing. And that could be a part of a research program or participation in research. It could be a part of

a genetic counseling encounter. When you decided to make a move into industry after working in the

clinic, and I think you did that a couple of years ago in 2018, did you notice and see some health

disparities there and kernels of systemic racism or flat out, in terms of the testing itself or how it was

marketed perhaps to different people?

**Altovise Ewing:**

Yeah. So I definitely follow disparities and differences upon walking through the door. And that was

actually something that I was very cognizant of once I accepted the role. When I saw the commercials or

even read about the product, it didn't always resonate with me, or I didn't always see myself or I

questioned, how will this really benefit my family?

**Altovise Ewing:**

And I am very grateful that the company I worked for was receptive to that. And although it took some

time, I can say that gradually, I made progress in terms of helping individuals to maybe see a different

side of the story, or maybe to take into consideration a different angle or how a particular report may be

perceived by an underrepresented group or an underserved group.

**Altovise Ewing:**

And even just acknowledging how I, continuing the practice of availing reports to individuals of

European ancestry, and not always taking an equitable approach to avail tests or results for groups that

are disproportionately impacted by a particular disease, how, unfortunately, although we may not want

to admit it, that maybe us contributing to the problem, as opposed to helping to post solutions.

**Altovise Ewing:**

But as I mentioned, it was something that I was very cognizant of day one, walking through the door,

and it was something that I was able to check in and something that the company was very receptive to,

in terms of connecting with experts who worked with various groups that were underrepresented in the

genetic testing and genetics research space, or even attending various events where we could better

connect with various groups.

**Altovise Ewing:**

So those were definitely some of the steps that we took, on top of being involved in various podcasts

that would reach audiences of underserved and underrepresented populations. So we really tried our

best to take a more active and responsible approach in reaching underserved and underrepresented

groups.

**Altovise Ewing:**

And although the genetics field in general has a long ways to go, I can say that those small steps were

additive. And I think it's something that the company continues to this day. I actually had a chance to

see that a paper was published recently, that focuses on racial and ethnic differences as it pertains to

COVID-19. So it definitely leaves a warm feeling in my heart to know that some of those efforts that I

started championing back in 2018, remain with the company today. And that the company realizes that

team science is the best approach in terms of helping to drive health equity and advance inclusive

research.

**Deepti Babu:**

Yeah. I mean, you've just given a couple of examples of how those of us in the majority can work toward

dismantling the disparities and really habits. I mean, it's truly laziness, honestly. I think it is. I'm just

going to call it out. Because I think it's just doing what's easy, it's doing what's comfortable.

**Deepti Babu:**

So it's like, forcing yourself to think differently, listen to different people, engage with different groups

that you maybe don't have a lot in common with at first glance. And building those relationships is the

only way you're going to be able to build the trust, which you also referred to as a vital component. If

you don't have that, you can't really build anything on it.

**Altovise Ewing:**

Yeah. And I would definitely agree with you that it's a sense of laziness. And unfortunately, I would say

there's a sense of fear behind it as well. Because I think it's a new way of thinking, it's a new way of

acting. And unfortunately, there is not a playbook that one can put in someone's hand and they can

follow that from beginning to end and be guaranteed a successful outcome.

**Altovise Ewing:**

It is going to require, again, true partnership, collaboration. And you may encounter some hiccups along

the way, but just the science is very iterative and we learn from our mistakes or we continue to build

upon the progress that we've made. We have to take the same approach when it comes to ensuring that

we are being more inclusive of underrepresented and underserved populations. Because again, the

science depends on it, health equity depends on it and quality of life for all populations depends on it as

well.

**Altovise Ewing:**

So it's a sense of responsibility that we have to own and we have to walk into. And it's one that can be

achieved. We can definitely get it done. And I look forward to the day where health equity, where it's no

longer a specialty. It's not anything that we have to focus on because it's [crosstalk 00:23:58]. Yep, it's

the norm. It's naturally ingrained into everything that we do.

**Deepti Babu:**

Right, right. It's just infused into it because we've thought it through. And also, you talked about the fear

there, I think it's the fear of making a mistake as well. And sometimes that means the profits are on the

line if you make a mistake or revenue is on the line. And so when you think about it from the

perspective of a business, you feel like you're taking a risk and if you're going into uncharted territory,

that that can be scary.

**Altovise Ewing:**

Absolutely. But I really think that's where, as companies, especially when it comes to science and

medical advancements, we have to bank with ethics in mind, as opposed to thinking with that bottom

line in mind, because people's lives are at stake. Population's lives are at stake and they've been at state

for decades, for centuries. And we know how to do the right thing, it's just time for us to really step into

it and own it.

**Deepti Babu:**

So I wanted to get into a few concrete takeaways here. What are some things that folks who are

listening, who are perhaps thinking about genetic testing, or they're already in the middle of it, what

should they be aware of in terms of their overall experience? Maybe this could be in terms of the results

that they might receive and some caveats or limitations of those that unfortunately still exist. What are

some things that they could be thinking of?

**Altovise Ewing:**

Yeah. So one thing that individuals can be cognizant of is, if you know anything about your ancestral

background and your ethnicity, that information can help determine the types of tests that you're able

to access. It can help your healthcare provider select a test that is more specific to the needs of your

ancestral and ethnic makeup, because not all tests are created equal.

**Deepti Babu:**

Right.

**Altovise Ewing:**

And again, some of them are a bit more specific than others. But the more information that you're able

to provide on the front end, whether it's about your ancestry, your ethnicity, but also your family health

history in general, that's really going to be key in the type of tests you may be able to access and even

the probability that you'll be able to receive a result that will be clinically informative and one that will

help your provider determine the best course of treatment or best course of strategy for you to help

manage your medical care.

**Deepti Babu:**

I mean, that's true for just about anybody, but I can see how it would be vital for the underrepresented

populations.

**Altovise Ewing:**

And the other thing that I would encourage individuals, as they're pursuing genetic testing and genetic

counseling, is to really understand that genetic counseling is a non-directive profession. So we are never

going into the conversation determined to tell you what to do. We are there to partner with you to help

you make the best decision so that you are informed in the decisions that you take and the potential

outcomes that you can pursue.

**Altovise Ewing:**

And I say that because I want people to be encouraged to talk to their healthcare provider. So do not be

timid, do not be afraid to share any health information that you may have about yourself or about your

family health history, because the more information that's discussed, the more that experience will be

tailored to meet your needs.

**Altovise Ewing:**

And I think oftentimes, underrepresented and underserved populations may not always engage in

transparent conversations around health history, or even family health history. But that really could be

the difference between whether or not one is eligible to pursue a test. They could also determine if

someone accesses screening earlier than recommended for the general population and the frequency

by which someone undergoes screening as well.

**Altovise Ewing:**

So all of that is critically important information to really ensure that we're able to offer personalized and

precision healthcare in a way that's equitable for all populations.

**Deepti Babu**:

Yeah, that's great. And I would add too, because so many of those folks, I think this is, I don't know if it's

more common in underrepresented groups or not, but maybe there is like, half the family tree that

they're not aware of. What you were mentioning, where they may just not know one side as well as the

other, that's still important gaps of information. And so, tell your healthcare provider about what you

know, but don't feel bad if you don't know everything because nobody does.

**Altovise Ewing:**

Right. Absolutely. Yeah. And even that information that we thought was useful in the past, we're finding

out that maybe we need even more information on top of that. Or maybe we're finding out that some of

that information wasn't as useful as we thought it was in the past. So yeah, do not be afraid, do not be

ashamed if you do not know your comprehensive family health history.

**Altovise Ewing:**

The key is to have that conversation and that conversation can be ongoing. You may start the

conversation with your healthcare provider today, and you may need a couple of days or some time to

talk to family members and you can always bring that information back to that provider. So don't feel

like you have to have it in that one setting.

**Deepti Babu:**

Yeah. You might need to talk to your aunties and your uncles and whatever you need to do, that you are

in touch with them, that you feel comfortable discussing this kind of information with. If we then switch

over to maybe thinking about the perspective of someone who's a genetic test developer, marketer, or

medical professional, as they're thinking about framing genetic testing for underrepresented groups. Do

you think there's something that they can do to begin to shift their minds on how to approach it

**Altovise Ewing:**

Yeah. So I would say, as healthcare providers, it's very important for us to be aware of our own biases

that we bring to the table. I think that's where it has to start, just as we are required to undergo annual

continuing education courses, I think that the responsibility really falls on us and really our professional

society should hold us accountable to make sure that we're checking our unconscious and conscious

biases as well.

**Altovise Ewing:**

Because ultimately, that's going to impact our patients at the end of the day and it's also going to impact

the way that we interact with our healthcare professionals. And whether we realize it or not, patients

can sense if you are uncomfortable with them, based on maybe their socioeconomic status or their

ethnicity or cultural practices or habits. And unfortunately, that can also hinder a patient's ability to

open up to a healthcare provider and to even trust the healthcare provider.

**Altovise Ewing:**

So I think it's very important for us to be aware of those biases and to constantly challenge ourself and

check ourselves and have difficult conversations with friends, with colleagues, and with people that you

may not interact with on a day-to-day basis, because this is going to help us all be better providers, so

that we can meet the needs of all of our patients, all of our populations.

**Altovise Ewing:**

But the other thing is, that people should understand that you don't have to do this alone. Although our

profession is predominantly white, there are a number of us from underrepresented and underserved

populations, who have been on the ground with underrepresented and underserved populations. And

we've been able to help develop some of those best practices and strategies, as well as tool kits to help

us better engage underrepresented and underserved populations.

**Altovise Ewing:**

So talk to us, we're more than willing to help share that information because we can all learn from each

other when it comes to this profession. This is a problem that we all have to address, and we all have to

work together to solve. And it's not something that people wish to keep secret.

**Altovise Ewing:**

And again, in order for us to really come up with solutions that will truly make a difference, we're going

to have to all work together to get it done. But I would definitely say, being aware of our biases,

checking our biases, and then partnering with our colleagues who come from different populations as

ourselves, or who may work with different populations that we work with day in and day out, that's

going to enhance our ability to better connect with more patients.

**Deepti Babu:**

I love it. Thank you so much.

**Altovise Ewing:**

Thank you.

**Deepti Babu:**

This has been a fantastic conversation. I feel like we could just keep going and going, but did you want to

share with folks how they might be able to reach you, if they wanted to connect with you on social

media?

**Altovise Ewing:**

Yes, absolutely. Whenever I do have free time, I always love connecting with people. You can find me at

Altovise Ewing on LinkedIn. On Facebook, I'm Altovise Ewing there as well. Twitter, my handle is

@altovisee. And then on Instagram, I am the\_social\_scientist.

Deepti Babu:

Well, thank you so much for sharing all this great insight and I hope that we can all work together to

make science less convenient.

**Altovise Ewing:**

Yeah. Absolutely. And thank you for the opportunity, Deepti, for focusing on such an important topic.

Like I said, I'm very hopeful and optimistic that the changes that we've been desiring for some time, that

they are definitely going to manifest within the near future.

**Altovise Ewing:**

I feel like more scientists and more clinicians are putting ethics first. And I feel like our patients are only

going to benefit and are only going to see some of the tremendous advancements manifest in their life

more immediately as a result. So thank you. It all starts with these conversations. It all starts with

disseminating this information. So I'm very grateful.

**Deepti Babu:**

I just wanted to recognize three podcasts that have delved into, not this exact same topic, but topics

that are somewhat related. One of those is the NSGC podcast series. For its August episode, which

talked about diversity and inclusion in genetic counseling. The Genotype podcast from Grey Genetics,

which in its September 3 episode, features talking to a genetic counselor on her experience of being

black in the field. And The Beagle Has Landed podcast with genetic counselor, Laura Hercher. The July 6

episode is discussing racism in genetic counseling, with two genetic counselors. So there's lots of great

stuff out there as well.

**Deepti Babu:**

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