Genomics and Global Health: Promise or Peril?

Patricia Kuszler, Charles I. Stone Professor of Law
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Dean Hicks: Hello everyone and welcome. This is another in our series of installations of named professorships here at the Law School of the third of the Charles I. Stone professorships.

Earlier we had installations of Professors Jane Winn and Lou Wolcher in Stone professorships. And it's just a real expression of the generosity of the Egtvedt family that we now have our third installation that has been made possible by this gift, our colleague Patricia Kuszler, who will be coming to the podium soon and making her speech.

But, I just wanted to recognize a few guests and visitors here, who are with us here today. Carol and Richard Stone, the son of Charles Stone are here with us today and alumni from the University of Washington Alumni Association, the Washington Law School Foundation, including the Chair of the Foundation, Joe Brotherton here and members of the Perkins Coie Law firm.

One of the extraordinary things about this gift is that the gift was made to honor the Egtvedt's longtime legal counselor, Charles I. Stone. Just think of that, a donor choosing to make a gift to honor their lawyer and the services of that lawyer provided over many years.

Jim Lisbakken will be speaking to that a little bit later on. And so, a member of the Perkins Firm, formerly Perkins Coie Stone Olson Williams and Mr. Stone was the Stone of that list of names. For those of us who knew him both as a mentor and a lawyer, nothing could be finer really than to have a professorship that carries his name.

Again, Jim will be speaking to that a bit. Jim Lisbakken will be coming to the podium in just a bit.

I said on the earlier occasions of these installations and I will say again, just a huge importance of this type of gift to the Law School. Not only is it a way of just stating in a very, very forceful way the quality of the work that our colleagues are doing but it really does put wind in their sails, allowing them to have the capacity to hire research assistants, to do travel in support of their work and to bring colleagues in their fields to come here to the Law School.

I think, we are beginning to appreciate just how important it is for the Law School to be at the center of the scholarly conversations that matter and to have an endowed professorship that allows the holders of the chairs to really turn this Law School into a platform for those sorts of exchanges of ideas. It's just very, very important and special to us.

So, the vision that goes into supporting a gift of this sort is extraordinary and very welcome. So
we thank the Egtvedt family for that in particular.

So, I guess, with that I will turn over the microphone here to James Lisbakken, an old friend and a partner at Perkins Coie. Jim has been a partner at Perkins for some years now working on licensing and technology issues in chief.

He has his undergraduate degree from Oregon State - go Beavers - and his law degree from the University of Oregon. So Jim and I were just talking and sharing notes from our time. I started out in Seattle as a fledgling associate at Perkins Coie and knew Jim then. We have been happily comparing notes from those days.

So Jim, please your remarks now on Charles I. Stone.

[applause]

Jim Lisbakken: Thank you very much Dean. By the way, I just came in on an airline last night and we were supposed to remind people to turn off their cell phones.

[laughter]

I got to know Chuck Stone as a very young associate, having come up from Eugene - I was at their law school - in the mid-70s. Chuck had a practice in estate planning and probate and we all looked up to him.

I remember his easy smile, his friendly character, and his taking young associates to lunch. We also engaged in many lengthy discussions with him from time to time. And we just found him a great pleasure to be with.

Those were those early years. At that time the firm was known as Perkins Coie Stone Olson and Williams. It was only in '85 that we finally changed the name.

He seemed to take a special interest in all of us and I think, there are two aspects of his career that still live on at the firm. One aspect was his devotion and commitment to the practice of law but also to public service.

He was President of the Washington State Bar Association and President of the United Way of King County in addition to being Chairman of the United Way of the United States. That service has now been carried on by other people in the firm, other lawyers. I think, that I always think of Chuck as being the one that led the way.

We also looked at his service as President of the Bar because in those days we wanted to pass the Bar and he gave us the early tip before the envelope arrived that it was OK, "You're going to pass the Bar exam."

The second aspect that the legacy that I see at our firm that Chuck left was the continuing culture that he ingratiated in all of us and the graciousness and steadfastness. And that has carried over. I
attribute it partially to him that today we have a culture that is recognized by Fortune Magazine as having received in the last six years continuously the award of being one of the best places to work of 100 companies in the United States. Now I think, part of that really has to be attributed to Chuck and his guidance.

In his senior years at Perkins, there in the early 80s, he saw us starting to practice in the medical sciences area. We took on some new clients, some clients that needed to be formed, financed and in need of legal services. It was then that the biotechnology evolution was occurring in Seattle with the formation of Immunex and Genetic Systems.

I think, if Chuck were around today he would be very engrossed in the subjects about whom we are going to hear today - bioethics, biotechnology and some of these related subjects. I think, it's quite an honor that we will have those subjects discussed by our inductee today.

The three professorships that have been awarded in his name I think are a recognition and tribute to his character and devotion to the long-term interests of clients. I always thought of Chuck as doing it the right way. That is in 1985, when he passed away he was still in his boots as I would say. He was still acting as a lawyer. He was presenting an oral argument to the Washington Court of Appeals.

To me, that was a superb closing act and something that I always remember from my years knowing Chuck.

It's now a pleasure for me to introduce Peter Nicolas, the Jeffrey and Susan Brotman Professor of Law. Peter joined the faculty of the Law School after a clerkship at the US Court of Appeals for the First Circuit, which followed after his graduation from Harvard University School of Law and did his undergraduate work at the University of Michigan.

I'm told that a number of his scholarly works have been strongd in many court opinions, including the US Supreme Court, a number of circuit court cases and Federal and State cases. Peter.

[applause]

**Peter Nicolas:** Well good afternoon everyone. I've had the distinct pleasure of knowing Pat since I started here at the University of Washington eight years ago as an assistant professor.

Over the past eight years I have had the opportunity to get to know her in a variety of capacities, as a mentor, a colleague and of course as a friend. It's really my honor to introduce you to her today.

As some of you may know, being a lawyer/law professor is actually a second life or a second career for Pat, who in her former life was a doctor. She went to the Mayo Medical School right after college. That is the Mayo as in the Mayo Clinic where the rich and famous go to illnesses, whether real or imagined treated.
After her time at Mayo, she spent 10 years practicing emergency medicine. It was really this aspect of Pat's past that I think, attracted me to her as a friend.

As a young child, a son of a doctor, it was assumed I was going to grow up and become a doctor. So it was really interesting for me to know this person who left what I thought was going to be my career for what ended up being my actual career. So there was that curiosity.

There was also, I have to be honest, a practical aspect to it. When you grow up the son of a doctor, you are pretty used to just turning to dad when he comes home from work, before he has a chance to take off his shoes, you open your mouth and say, "Oh there is this thing in my throat. Can you tell me if there is anything I need to worry about? Maybe you can write me a prescription for some antibiotics."

So you can imagine my chagrin when I discovered that Pat had actually given up her license to write prescriptions.

It turns out this is less of an issue in this day of technology. My younger brother has the same bad habit that I do. He has now taken to using email to simply send pictures of his throat or his leg or his arm to my dad to say, "OK. Tell me what this is."

But, why did Pat leave medicine? For one thing she was, as many people are, burnt out after 10 years of emergency-room practice, witnessing the first hand limitations of the healthcare system. I think, it was time for a change.

She also told me she was bored, which really tells you something about Pat and I think, her need to constantly be challenged by new things. As I understand medicine, there are many aspects of it that can be boring. But, I think, emergency room medicine is rarely thought to be one of those.

So ever the underachiever, she decided to go to a small Law school in New England. Some of you may have heard of it. It's known as Yale Law School.

When I went to Harvard Law School I was told Yale was the big rival and you have to go to the Harvard/Yale game. I went to one and, having been an undergraduate at the University of Michigan where we had really serious rivalries it was hard to take very seriously the aggression between the Harvard and Yale students.

Pat fell in love with law. I think, that's fair to say. She found Law school to be intellectually fascinating. And of course, after law school she spent just under four years practicing law in the
District of Columbia at Hogan and Hartson.

In fact, she tells me she loved law school so much that if they would have paid her she would have just stayed there forever. That's essentially what she has done and what most of us in the Academy have done.

She has become a law professor. But, with all of this background, Pat really has a unique contribution to make to the Academy. Not only is she a combined MD/JD, which is rare today and was even rarer still at the time, but she has actual practical experience in both fields, which is even rarer.

She entered both of those fields at a time when I think, it is safe to say that women had not yet begun to populate either of those fields in significant numbers. So it's an achievement for a variety of different reasons.

Once Pat joined the faculty in 1994, she quickly advanced in the ranks, achieving the rank of associate professor with tenure four years later and full professor two years after that.

Since joining the faculty, her accomplishments have been substantial. I'll try to name just a few. You really often feel lazy as you go through her list of accomplishments.

One thing that she is of course well known for is setting up and maintaining the Health Law Program here. She has created a Health Law concentration track for JD students and she is currently trying to put together an LLM program to attract students from across the country and the world.

She is interdisciplinary work. She doesn't just do interdisciplinary work. She has worked with schools as diverse as nursing, medicine, public health and international studies. She holds adjunct positions in several of those departments.

She has brought the Law school on board in collaborating for the Public Health Genetics Program, which is a degree granting program. It involves seven different schools across the campus.

She managed to get me into the act of interdisciplinary teaching, which is a challenge because I tend to be a skeptic of the buzzword 'interdisciplinary' when university administrators talk about it.

But I think, what she does really is where interdisciplinary work can be helpful. She persuaded me to teach Evidence Law to nursing students. I agreed to teach a joint class between law students and nurses and it was fascinating.

I think, by the time we were all done, the law students learned something from the nurses, who had much more practical experience being in court than any of them and certainly their professor has.
The nurses had all of these 'aha' moments. They had been testifying for years and as we would go through the material they would discover why the testimony they were trying to give was excluded. So I really enjoyed that opportunity.

She teaches so many courses. She has, I think, created 16 new courses since she joined the faculty. She always teaches an overload. Even when she took on the role of Associate Dean I think, she taught something like six courses per year or that particular year.

So, those are some of her accomplishments. She also was Associate Dean. I have to give a mixed verdict on that, not because of the quality of the work she did. The taxpayers of Washington should be very pleased with her performance.

But when you have a friend, if you have to have a friend go into the office of Associate Dean, you really kind of want your slacker, underachiever friend as opposed to your hard-working, overachieving friend. Going to Pat as Associate Dean and saying, "Oh, could I have slightly less of a teaching load because I've got these new courses I'm teaching?"

She wouldn't yell at you. And she wouldn't say no. But, she would just say something like, "Oh, come now Peter. Really. You are about to advance to the ranks of tenured professor. Are you really sure you can't handle teaching a full teaching load next year, which - I'm teaching more by the way and being Associate Dean at the same time?"

She is also [inaudible] rainmaking is not something you normally associate with academia and law schools in particular. But, she is a major rainmaker for the law school in terms of bringing in outside money. I think, currently she brings in enough to cover her own salary and those of maybe three or four other faculty members.

She does all of this while publishing, on average one publication per year I would say, whether it is an article, a book or portion of a book, and taking an active role in service and in particular initial appointments, where she has played a major role in recruiting and supporting young faculty.

Now you might imagine with all of those accomplishments she really has little time to do much outside of work. But, that's not really the case. The fun thing about Pat is she is the person you can always go to if you want to try something new and fun that most people think is strange.

For example, when I first moved to Seattle I discovered that my way of avoiding stress I think, was going to auctions and bidding on things to fill up my house. I could somehow not persuade any of my colleagues to go except for Pat, who thought this was an interesting thing to do.

I remember on this one occasion she came with me. Somehow we got into bidding fever and I won a piano and a chandelier.
This raised several problems for me - one, of course the practical of how to get the piano home. Then there was the fact that I didn't know how to play a piano. That presented another issue.

Then the chandelier - I was looking for the plug and the light switch and I didn't see either on it. For those who know me, I'm not really very facile when it comes to home improvements. I'm still looking for someone to change this light bulb in my bathroom that goes out once every three or four years. I have to trick some houseguest to change it by sending them in there when they have to use the restroom.

[laughter]

And saying, "Here's the light bulb incase this goes out when you go in." It turns out Pat didn't really help me with getting the piano home or learning how to play it but I learned that she is of unbelievable assistance with the third.

It turns out in her spare time she can do just about anything involving home-improvement. She can tear down walls, build walls, install electrical appliances and all sorts of other things. So I found well, she doesn't have a prescription pad but I suppose that's the next best thing.

So she helped install that light fixture in my dining room. So I can now actually see when I eat in there.

She's also a great travel agent. I often consult her when traveling because she had managed to be in all sorts of places.

I remember shortly after she became Associate Dean, I had to have a very important meeting with Pat. I said, "Can I have an appointment?" She said, "Yes."

And so I came in and I said, "I'm going to the big Island of Hawaii and I need six days worth of itinerary." She was amazing. She gave me the list right off the top of her head of everything to do, including getting a specific doughnut at a particular bakery.

[laughter]

All of her advice was absolutely perfect.

Really the bottom line I guess I would have to say is, if you only know the serious, hard-working Pat, you're really missing what I think, is the best part. So with my time I think, at an end, I just want to close by saying it is an honor and pleasure to introduce you to Pat Kuszler as the Charles I. Stone Professor of Law.

[applause]

**Dean Hicks:** Thank you Peter for those wonderful remarks, touching not only on our wonderful colleague but hypochondria, football rivalry and impulse shopping.
[laughter]

So that was really quite an accomplishment. Anyway, thank you. Just lovely remarks and richly, richly deserved.

So now I will introduce our speaker at the occasion of her installation as the Charles I. Stone Professor of Law. I have a medallion here too, that has on it completely and says all it needs to say, "Charles I. Stone Professor, Patricia C. Kuszler".

It's my great pleasure to bestow this on Pat. It's just an emblem of the Professorship that she is now stepping into.

[applause]

Pat, the podium is now yours.

**Patricia Kuszler:** Well I want to thank you so much for this wonderful honor. I want to thank James Wisk Baden for his comments regarding Charles Stone. It's truly an honor to have his name on my professorship.

I'm particularly pleased that some of the members of the Stone family are here today. I also want to remember Claremont and Evelyn Egtvedt who gave the money for the professorship, which I think, is indeed a dramatic testament to Charles Stone.

I want to thank Peter for his wonderful introduction. I'm especially appreciative given the fact that Peter just returned from Europe last night after having got advice from me of course on his trip.

[laughter]

And still delivered it with such aplomb.

I also want to thank Dean Greg Hicks, who has been so supportive of me and my colleagues in our research and teaching ventures over the last several months that he has been Dean. I also want to thank our former Dean, Dean Joe Knight, who nominated me for the Stone Professorship.

As most of you know from Greg's introduction, there are three of us. I think, it's a real tribute to Joe that the three of us who have Stone professorships couldn't be more different in terms of style and scholarship. I'm hoping that Charles Stone and the Egtvedts would be very happy about the breadth and the scope of the work that their gift so generously supports.

I also want to thank all my colleagues and friends here at the law school and throughout the university. As I look around the room I see many of the friends who have made my work here so intellectually rewarding as well as fun. It has been a great good time and many of us have shared not only scholarly insights but also a great deal of humor over the years.
I've also had the great privilege to have an ongoing academic partnership with many other programs across the campus. This has truly been a blessing.

I want to especially thank those from the Institute for Public Health Genetics, the Northwest Center for Public Health Practice, the Center for Genomic and Healthcare Quality, the Department of Medical History and Ethics in the Med School, the Department of Health Services in the Public Health School and of course, the School of Nursing. We have ongoing programs with all of these wonderful entities.

It wouldn't be complete if I didn't give a special thanks to our terrific library. We are blessed with a group of superb law librarians, who are indispensable to all of us on the faculty. I can't imagine how difficult our lives, scholarship and teaching would be without their help.

They are able, inspiring, and truly brilliant. To give you an idea of their brilliance, one of those reference librarians taught Peter how to play that piano.

[laughter]

I also want to especially thank our administrative staffs who keep our academic enterprise running smoothly. I want to single out Jennifer Snyder, who hopefully is still here - yes - who manages our Center for Law in Science and Global Health, including our Health Law Program and all of its many research and teaching ventures.

Jennifer was also our primary administrative assistant when I was Associate Dean and I shamelessly stole her when I left that office to run our Health Law Program.

I want to also mention Bill Thornton and our business office staff. They have helped Jennifer and I learn about the incredibly difficult and intricate world of federal funding. We would never have been able to expand our Health Law Program as we have without their help.

Finally, I want to thank Vicki Parker and Kim McAliffe who provided valuable help to me and 17 or 18 other faculty members, for whom they are the primary administrative support. They help us with our classes and getting our materials together on an everyday basis. We would never be able to keep our students and our courses running without them.

And finally of course I want to thank all of our wonderful students who help me and our Law School constantly grow and diversify. Many of our courses and many of our research initiatives in the Law School and particularly in the Health Law Program have been inspired and indeed spearheaded by students.

They are a constant source of energy and great ideas. A couple of the courses that we have in our Health Law repertoire actually were suggested by students and indeed heavily researched. The first syllabuses actually were written by students who really felt this was an area in which we should have a course.
One of those was Disability Law. Another one was a course focusing on issues at the beginning and end of life.

So as I have gone through this entire cascade of wonderful people, I want to say how lucky I have been to work with all of these partners, colleagues, staff, and students on all of these wonderful enterprises.

Now I would like to spend a couple of minutes, a little bit of time to give you a bit of a flavor of what we have been doing in our Health Law Program here at the Law School over the last 14 years that I have been here.

So I'm going to talk about two of our projects, one that started at the beginning of my time here and one, which we have just undertaken over the last few years and talk a little bit about how they link together - genomics and global health and how they grew and how our students and faculty are looking at legal issues within them.

The first one of these is our Institute for Public Health Genetics. This collaborative education endeavor came our way the second year I was here when the University decided to have a University Initiative fund where we could vie with interesting new programs and get University money to support them.

So, we collaborated with six other schools in the University and put in an application for such a program. Essentially our application was funded and it has now grown into our Institute for Public Health Genetics that has a Graduate certificate, two Masters Programs and a Ph.D. program.

We are in our 10th year and throughout that entire 10 year period our Law School, our faculty and our students have been thoroughly and actively engaged in this particular program. Indeed I think it has been a bit of a surprise, particularly to our public health colleagues that the very first few students, in fact their very first student is here today, finished their Public Health degree in Public Health Genetics and promptly went to Law School.

[laughter]

I'm pleased to say that in the years since, we have also had a number of law students who then decided that they too would get a Public Health degree in Public Health Genetics. They have all gone on to very interesting job possibilities in terms of biotech and the law, genetics and the law, working for legislatures and the like.

Indeed there is a cascade of wonderful, fascinating legal, ethical and social issues that are emerging from genetic science that gives us ever more fodder for our students. Literally every time we open a magazine, click on a TV news channel, or surf the Net we are going to find a new genetic discovery that is going to make our lives better and be glowingly reported in the news media.

Most likely the news story will say, "Oh, genetics is increasing our understanding of disease and
potentially will allow us to lead longer, healthier lives and it's going to be on your doorstep very, very soon, if not already."

If we look to the future, we see a realm of possibilities that both intrigues and amazes us. Everyday scientists are learning more about the genetic etiology of disease and beginning to develop genetic tests and treatments using genetic information and technology.

Genome research techniques, notably genome-wide association studies have yielded extraordinary progress in identifying the genetic contributors to diseases like diabetes, heart disease, breast cancer, and many other chronic disabling conditions that are likely to befall all of us as we journey down life's path.

Some of the earliest benefits in this world came about in newborn and prenatal screening. We now routinely are able to provide carrier screening and prenatal testing to assist would-be parents in their quest for a healthy child.

Another early victory in the world of genetics and medicine comes in the context of newborn screening. We now routinely in all 50 states test for phenylketonuria, a genetic disorder that makes it impossible for an individual to break down phenylalanine, an amino acid that is in pretty much all foodstuffs that we typically eat.

With dietary adjustments, these kids can lead long and healthy lives. Without a special diet they will be profoundly impaired. So now all 50 states have legislation that requires, indeed mandates testing for PKU so we pick up these children very early and get them on the appropriate diet so they indeed do not suffer developmental delays and mental retardation.

This is a wonderful thing. Indeed as science has progressed we have now an ever-growing number of tests we can do to find genetic disorders that appear in the newborn and hopefully be able to treat some of them. I'll come to that in a moment.

Multiplex technology such as tandem mass spectrometry allows testing for many diseases at one time, one sample, one pass through the machine. So, this is a huge area of benefit for people and indeed for populations.

We also have the capacity to do genetic testing to determine susceptibility to certain diseases. The big one out there of course, you probably heard about, which is testing for BRCA one and two for breast cancer. There are a small percentage of patients in the population that have this particular mutation. If we know about it we can help them engage in more rigorous surveillance or even prophylactic surgery.

In one of the even more promising areas of genetic research, scientists are now learning how our genetic makeup affects the way we respond to drugs and are beginning to tailor drugs for individual therapy, informed by the genetics of the disease or indeed of the individual patient. Some of these drugs have already been applied in the treatment of childhood cancer, offering a clear benefit to these critically ill children.
Outside the medical context, genetic analysis has provided an opportunity for more precise and accurate identification of victims, criminals and those erroneously convicted of a crime. This is one of the most dramatic and successful use of genetic technology.

Our colleague, Jackie McMurtry leads our Law School's Innocence Project and works in this cutting edge area of criminal law. As Peter mentioned, Jackie and Peter and I worked together on the Forensic Nursing Program, which had as its focus training nurses to recognize and preserve evidence as they care for victims of violence.

So, with all of these wonderful advances in genetics, where is the peril and what part does the law play? Even with enthusiasm over these early genetic innovations and opportunities, there is some cause for concern and some downsides. Indeed, a wonderful array of legal, ethical and social issues for our students and faculty to explore.

Despite for instance the spectacular successes with forensic DNA in the courtroom, there is a concern that one day down the road genetics might be used more perversely, for example, a genetic defense of 'my genes made me do it' to mitigate culpability, or alternatively, the use of DNA profiling to label and stigmatize individuals likely to commit a crime before they have actually committed it.

What safeguards need to be incorporated into the law to prevent abuse of genetic science and protect the rights of individuals, while simultaneously allowing victims an optimal opportunity to gain redress?

On the lighter side of DNA identification, there are a growing number of companies offering genealogic testing, DNA testing that allows an individual to identify their ancestral heritage, what island they came from in the Mediterranean, what country in Africa.

There is even a version of this for our pets. One recent story headlined, "What's your doggie made of?" and offered DNA testing to determine your pet's ancestry. At long last, for a great sum of money we too can know the pedigree of our alleged poodle.

[laughter]

But beyond the fun, this use of science, which we term recreational genetics, allows consumers to spend a significant amount of money for what is extremely speculative and scientifically unsupported data. Indeed, one could argue that consumer protection law may have a future role in addressing the exaggerated scientific claims of these test vendors.

In the world of prenatal testing, which I talked about so glowingly a moment ago, there is concern that the quest for a healthy child has transcended into the quest for a better child, a genetically better child, a designer child, even one with more nuanced testing that may be designed to be more socially desirable.

Already prenatal sex selection is a practice under the radar in many countries. There is fear that in the long run there may be yet more stratification of society on the basis of genetic traits. What
civil rights and other legal questions will arise as prenatal testing for more and more traits becomes available?

What justice issues arise in the context of access to these services? How will the law help to foster fair access and equity?

In the world of newborn screening, we can test for an enormous number of diseases or rather mutations. We actually don't know what diseases some of these mutations cause. Moreover, we don't know how to treat them.

So for parents, they may be confused and worried because there is no prognosis for treatment available to the parent. For the infant there is a risk they will be labeled as sick or imperfect in the eyes of their parents or society at large. They may be foreclosed from the right to what we call an open future.

For public health, there is the very real issue of whether public health law should mandate and indeed pay for a test that offers ambiguous knowledge and no treatment.

A different but equally troubling cascade of legal and ethical issues can present when we look at genetic susceptibility testing and predictability testing. In these cases the proband or index patient isn't the only one who is affected. Genetic information is at once the most and the least personal information.

How will this testing affect other family members, including future family members who would perhaps not wish to know their genetic destiny? What legal rights do third parties and family members have to the genetic information? Do doctors have a duty to breach confidentiality to provide family members with meaningful genetic information that might affect their own health care even though the patient doesn't want that information divulged?

There is already statutory and case law looking at some of these 'duty to warn' type issues across the country.

In the case of pharmacogenetics, the so-called genetic designer drugs that will offer individual sized therapy tailored to the genetics of the disease or the individual patient, this will lead to, optimists say personalized medicine, which James is currently working on.

Putting aside the question of whether such personalized medicine will refine or disable the doctor/patient relationship, there are even weightier questions of distributive justice. As we consider designer drugs, the ethical propriety of devoting massive resources to benefit a few, rather than devoting the same resources to benefit many cannot be ignored.

Suppose our designer drugs allowed someone to escape the ravages of male pattern baldness? Is that as compelling an aim as a drug that saves children or makes chemotherapy less destructive to children's' metabolism?

Can we justify devoting resources to male pattern baldness when those same resources could be
used to address an issue more determinative of health?

How will the development of designer drugs avoid ethnic and racial bias? Will they positively impact global health or merely draw down on resources to benefit only the populations of developed, industrialized nations able to afford these new innovative therapies?

This leads us into the substance of some of the issues that we are looking at the context of global health, particularly our Global Health and Justice Project within our Health Law Program. Our increasing focus in this area includes our Health and Human Rights course that attracts students from four schools, including law to work and learn in a multidisciplinary fashion about the role of law and policy in addressing global health.

Under the leadership of my colleague Beth Ribbon, we have a growing number of research and fieldwork opportunities for our students who are interested in social justice and global health.

It's ironic that just as we are inundated with new innovations in genetics, so do we see global health highlighted as one of the foremost challenges of the new millennium. And curiously enough there is an actual interrelationship between the two.

We can use genetic science as an illustration of some of the barriers to improving global health. As genetic science and research provide us with genetic tests, drugs and therapies for an even better, more personalized, more effective health care intervention, the promise of this genetic revolution is tempered by the growing concerned that these innovations will lead to a genomic divide much akin to the publicized digital divide about which we talk all the time.

The World Health Organization and numerous scholars are beginning to question whether the benefits of genetic science and biotechnology will inure to all or rather merely reinforce and deepen existing global health disparities.

This is particularly disconcerting in the context of genome related technologies that are tailored to the patient. If history is a teacher, such patients will likely be part of dominant populations in wealthy industrialized countries with robust, mature research enterprises.

The WHO estimates that low and middle income countries bear 92% of the global health burden of disease and account for 85% of the world's population. Yet 90% of the health-care expenditures are for diseases suffered by the populations of the developed, industrialized countries while only 10% of the global health budget is devoted to diseases afflicting the developing world.

This is sometimes referred to in the international health literature as the 10/90 disparity.

For example, sub-Saharan Africa accounts for 1% of global health expenditures even though it has the highest rate of childhood mortality and the lowest life expectancy, a life expectancy that is actually decreasing as a result of the wipeout of an entire generation by HIV AIDS.

In the pharmaceutical industries, there is a growing focus upon the lifestyle drugs as opposed to
those that target life-threatening disease. In the US and Europe, existing markets for lifestyle drugs are so large and so lucrative and pharmaceutical companies are able to generate large profits. Drugs for life-threatening diseases may be less profitable even in the US and the UK.

In the world of genetics this focus on the lifestyle side of the equation has already manifest. We see this in the personalized medicine ideal that is touted as a good thing from pharmacogenetics. We see in the recreational genetics world of ancestry testing and pet pedigrees and the like.

Unfortunately this means that the developing country needs are lower on the priority list. Between 1975 and 1999, only 13 of the 1233 new drugs marketed were for disease plaguing developing countries.

Even if advances in genetic science and biotechnology yield drugs or interventions to benefit the developing world, there are still phenomenal barriers. One of these is in intellectual property law, an area that many of our students are concentrating on.

Many developing countries are barred from access to genetic innovation by patent law. Unable to afford a license, even if the patent holder were willing to license the technology. Many poor and needy countries are simply closed off from access to biotechnology-based medical innovation. And patents covering most of the innovations in biotechnology are owed by corporations and governments in the developed world.

The 2001 Human Development Report noted that OECD countries with 19% of the global population accounted for 91% of the new patents issued in 1998. We have ongoing legal and human rights controversy on how patent law can be structured so that the rights of patent holders can be respected while allowing innovations and inventions useful to developing world could be made available to the very populations who can use them.

And although there are many scholars, law students, public interest advocates studying this topic, looking at compulsory licensing, merchant rights, public health necessity provisions, patent pools and a variety of product development and public/private partnership options, the fact is no solution has yet emerged in the law or in our policy making capacities.

Even if the barrier presented by intellectual property law were gone, there's a manifest lack of capacity in the developing world to make these drugs, to use these genetic innovations. Even if you could get a license, these countries could not manufacture or distribute the drug, given the lack of infrastructure and the ongoing political and economic strife.

In most of these countries, there's little government commitment or capacity to launch a publicly-funded biotechnology infrastructure to allow developing countries to get in the game, even as manufacturers of an already developed technology. This is exacerbated, of course, by the market brain drain from these countries, where talented young scholars and researchers leave those countries to go to the more comfortable and lucrative lifestyles of the Western world.

For example, 30,000 African PhD holders live and work outside their own home countries, many more than actually live and work in Africa. So, absent improved capacity of technical skill,
improved infrastructure and capacity building policy, the benefits of genomics and biotechnology are going to be a mere mirage for many developing countries.

Similarly, given the emphasis on lifestyle drugs versus life saving drugs, it's unlikely that priorities are going to be realigned to serve the life threatening needs of the developing world. Despite the bleak picture, there are some advances in genetic science that could benefit vulnerable populations of the developing world.

Notable among these is research that's going on with respect to mosquitoes. In 2002, the complete genome sequence for the mosquito-causing malaria was determined and the candidate genes that control susceptibility to malaria have been identified. Similarly, in 2007, the complete genome sequence for the mosquito that carries yellow fever, dengue fever and chikungunya viruses were sequenced and now the goal is to use this information to understand how the gene and protein functions and figure out the pathogen transmission mechanism.

In the throes of time, we may be able to engineer out the pathogen-causing capacity of the mosquito. In effect, building a mosquito that doesn't carry disease. Or, more likely or alternatively, using this information, we may be able to treat patients, making them less susceptible to the mechanism of infection carried by the mosquito.

It's sadly ironic that perhaps the real promise in genetics with respect to global health may line not with knowledge of the human genome, but that of the simple mosquito.

This sort of winds up my talk. And during the talk, I've tried to give you a snapshot of just a couple of the areas that our students and faculty are learning, working and researching in here at our law school. Over the last 14 years, I've had the pleasure of building our healthcare curriculum from a few courses into the Center for Law in Science and Global Health.

In addition to our JD concentration track in health law, we now have several multi-disciplinary concurrent degree and certificate programs serving both our law students as well as students from across campus. Our students come from the schools of public health, medicine, international studies, public affairs, business and the occasional student from anthropology and sociology.

Many of our students are also involved in our many research projects ranging from looking at the implications of genetics in terms of vulnerable populations, some of whom work on field to field working global health. But, essentially, our research profile is that we are actively involved and not only an ever escalating number of faculty. I think, everyone is a health law student or engaged in health law. But, also, our students.

Our students have gone on to become leaders in the local bar. I looked this up just for this talk and I found that the past president, the current president and the future president, the president-elect of the Washington State Society Healthcare Attorneys are all my former students.

[laughter]
And, indeed, more and more of our students are moving beyond Seattle and working at the intersection of law and science across the nation and abroad. During my time here, I've had the good fortune to teach and be energized by these wonderful students and work with an ever expanding universe of talented and diverse faculty and administrative staff.

We have the great good fortune here; we can mine this terrific university for opportunities for our students in our law school. I always say there is a legal implication or a twist to just about every discipline that's taught here. It's been a wonderful voyage of discovery for me and I thank you all for traveling with me on the journey and sharing this honor with me today.

[clapping]

Dean Hicks: Thank you Pat, so much and we've just gotten a bit of insight into the combination of compassion and commitment and rigor that have made Professor Kuszler's work really shine. And one of the things that we prize so much in Professor Kuszler and so many of our colleagues is they are constantly bring to us connections that we have not previously discovered and opportunities and possibilities that we have not yet seen.

And this is really the heart of the academic enterprise of looking to those who are out of the perimeter of the fields or out there in the high country and bringing to us some of the possibilities. The law school is very much committed to being a platform for these discoveries and for making these connections and extending the body of knowledge in the service of us all.

So, Pat, thank you for leading us in that and oftentimes being rather insistent about telling us about why and how we ought to move on opportunities that come our way. So, it's sort of nice sometimes to take those few points to the Dean's shins. So, it could be a very useful thing at times.

So, anyway, we're going to be going to the Perkins Coie room now and please stay, linger, talk, we've got some very nice refreshments and enjoy this good day. So, see you in a little bit. Bye!

[clapping]

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