\*Disclaimer: All transcripts are provided as a resource and are not guaranteed complete accuracy

I'm doing this in slightly reverse or the interesting intro and all that but there was a a kind of a message and I am

going to go back to this um sort of charming intro and it it's part of what

I mean by the slightly biographical story of this title it's my

perspective on a period of time back in the day and where we are now uh with

respect to a pretty impressive um set of Technologies and topics around genomics but when I say the older I get I don't

mean that in a strictly chronological way but in a biographical way the

sort of the more I sort of work through my own story the more I appreciate um that anything I've done or

been involved in has really been a result of people of particular people at

particular times making particular contributions um I mean I didn't even

recognize Rich Shriner when I walked in and I sort of looked at him and then he came up to me and said hi Eric I'm rich Shriner from Pediatrics

it's like saying hi I'm Jesus Christ maybe you're familiar with me um some

people think that that's who it is um but this for those who weren't here back

in the day uh you know you'll see later that there are more of them but there were some fairly influential

people uh and I would say but for them at a particular time a lot of the stuff

that Peter just mentioned including my coming to IU would not have happened and that is including people like miles

brand the former president who was quite um Visionary and risk-taking and

thinking about something odd like bioethics on a different campus um you know our much beloved

former IUPUI Chancellor Jerry Bepko who just passed away recently um who was

quite influential both behind the scenes or in the in the room next to the room where things happened um of course Craig

Braer and Ora Pescovitz uh I can't say enough about their kindness and their

creativity and uh and thinking you may not know all the other people um

below them but uh Herman Saamp was a dean of liberal arts quite Progressive

and in fact Herman was the one who called me while I was still working in Washington DC and said you don't know me

but a friend of yours named Jonathan Moreno told me I should call you so it's all about people Angela McBride um just

a spectacular dean of nursing Norm lefstein was the dean of the law

school and we've already mentioned my good friend Bill Tierney who's at the back uh you may not know the Yoda Likee

figure on the right some of you will know the Yoda Likee figure that's um Dr Edmund Peligrino um and Dr Pellino in

addition to being one of my mentors at Georgetown and a legend and true

founding father in the field of bioethics um unbeknownst to me was asked

by and Bill may have been on this committee he on every committee known to IU to come I think in the uh the mid

2000s and do a site visit on this campus and essentially assess its capacity for

uh establishing some kind of bioethics activity and the way that Pellino told me

that he told IU is you would be crazy to not do something here you've got the largest medical school in the country

you've got all of this stuff going on nobody knows about it the sort of joke about Indiana flyover State and all the

rest of it but Pellino who established two medical schools um you know was a

was a medical advisor to the pope was the former president of Catholic University uh I mean he was the real

deal uh and practically invented the field of medical Humanities uh from a

from a physician's perspective and he sort of read IU the riot act uh and said

you would be crazy if you didn't do something so in many ways I'm just the

the product of a of a much longer uh conversation that was held by

people who were prepared to take certain risks at a certain at a certain time so that's why I um slightly humorously but

wanted you to know why I I began with that so this was the title that Peter and I worked out a little bit of looking

in the past and looking uh to the Future um I do want you to know a few

things I won't read the whole slide but I do a bit of work for the OECD um I'm

very honored I'm GNA get a small stipend for this visit um but I have a number of

affiliations uh not in only at the Council of Canadian Academy a mouthful that no one ever says correctly U but a

few other academic affiliations and the standard disclosures that these are my

words they may agree with them I hope they do but um this is this is

essentially all me um I love this quote from Mark Twain

because we spend a lot of time thinking that we're looking in the past

and we had this kind of rose-colored view of it's always better back then whatever back then was or we say we

should in the case of something like pandemic preparedness Chad I'm looking at you buddy um you know let's learn the

lessons of the past and make sure we don't repeat them it's a tiresome phrase I think it should be retired because I

don't think anybody knows what it means to learn a lesson they don't know what the lessons are who's authorized to

teach them how we know when they have been learned and when the curriculum needs to be revised so you know I

wouldn't mind to declaring a moratorium until people understand what the hell they mean when they say um we're going

to learn from the past and not repeat those um those failures and of course we will we'll absolutely um

recognize and repeat um easily all of the successes um good luck but I don't

think that's been happening this this captures for me on the other hand a kind of We aren't starting from scratch every

time and those of us who don't remember I'm not using the

quote about those who forget history are doomed to repeat it that's not the point it's that this is all part of a story um

and I just kind of entered the story at a particular point in time um with a particular set of opportunities um at

what I think was a quite exciting time for the IU Medical School um for the

field of genomics and I would say for the field of bioethics um I know that humans like to

have origin story that start at a particular time and it's very hard um to

get agreement on what the origin story was for a field like genomics clearly

there has been genetics research in genomics for quite some time this is a slightly uh why does that say talking

Eric meslin covering up Bill Clinton's words technology is supposed to be our friend can I move

this philosopher that's the extent now I did make all these slides so that's also the extent

of my ability what you're seeing here is a little bit of a complicated slide but

hopefully if you've read a bit over my shoulder you're you'll know what it is

um on June the 26 2000 uh Bill Clinton convened about 120

people in the East room of the white house uh I was fortunate enough to be one of them where he brought Francis

Collins pictured on Clinton's left or your right and Craig Vinter pictured on

his right your left to announce that the rough draft of the human genome had been

sequenced the rough draft this was a diplomatic a

datum because the sequence hadn't been finished but there had been a parallel

quite public competition self fight between the public Genome Project led by Collins uh

at all uh not only at NHGRI but elsewhere at several important sites

around the country and around the world meanwhile Craig Venter running the organization called

Solara genomics using a different method of trying to figure out um the uh

location and alphabetic Order of the genome was getting very close and

there's a much longer story that we don't have time to tell but an agreement was reached that on this day they would

both show up in the East room uh Tony Blair was on a big screen behind them

from number 10 Downing Street where they chose to say this is the day it could have been the day before it

could have been the day after there's nothing magical about the day um as a date but what was quite magical

irrespective of your feelings about Bill Clinton I would urge you to YouTube this

announcement where even to this day it sort of sends a little bit of a a chill up my spine

where he said nearly two centuries ago in this room on this floor Thomas Jefferson and a trusted Aid spread out a

magnificent map a map Jefferson had long prayed he would get to see in his lifetime he was of course speaking about

Lewis and Clark coming back from the west and the this the foundation slide

Foundation background for this slide is part of the report from Lewis and Clark uh Clinton had some excellent

speech writers as I think you can tell he also had a gift for um for rhetoric

and public speaking and when he said we're here to see without a doubt the most wondrous map ever produced by

mankind the first survey of the entire Human Genome it's kind of hard to

top that using um the rhetorical tools of metaphor and analogy um and similar

to be able to say that happened then I'm just part of a long chain of Chief

Executives that have welcomed science into this room like there's a lot to unpack I'm not going to do all of it in

the slide um the map of the opening of the West Was lifechanging for the

United States and arguably the map which you'll see this is the picture of the of

the rough draft underneath the nature science and time magazine covers

was arguably um of equivalent uh impact at that time lots

more happened after that date um arbitrary dates like the first working

draft and then the completed draft so these were um in a sense marketing

strategies for reasons unrelated to we're just announcing the publication of something we found in an academic

Journal this had much more going on it had International diplomacy it had it was a movie I mean

there were behind the scenes fights about who would stand on which side of Clinton at that meeting who would appear

on Time magazine in front and behind who would be publishing in Nature and Science all of this was

negotiated this didn't go through regular peer review um Ari Patrinos then

the director of the Department of energies Genome Project

allegedly uh engaged in the equ equivalent of what we called Pizza Shuttle diplomacy where he invited Collins

inventor to his home in Gaithersburg Maryland over Pizza over several weekends to try and hash this

out right so in some ways this uh slide

says more than just what's on it and I I would love to say a lot more but I would say for me it was a pivot point in How I

thought about the role of science ethics and policy to see you know two world

leaders uh at the same time a room full of everyone Jim Watson was in the

front row and if you watch the video as often as you want you will see Clinton

walk in turn his head to Collins and Co and Collins will

go like that and then then in the middle of Clinton's introductions he says it's

really nice to see Jim Watson having just asked Collins where's Jim Watson

that's how sort of good Clinton was on his feet but also

how important it was after he recognized all the diplomats and all the whatevers and the whomever I was basically sitting

sort of where Matt Rotelli was maybe a couple rows back maybe where Chad is in that room it was no bigger than this

and it was an electric sting and obviously you can tell it still had a an impact on

me come on was it like because I took too long and it walked

up okay fine um just using the dipping into

the you know the Clinton files for a second this is a slide that reflects also many things going on at

one time the topic of embryonic stem cells became another accelerant in the

public discussion of Science and genomics it was the result of two

different Laboratories in two different places in Wisconsin and Hopkins being able to identify and derive embryonic

stem cells and embryonic germ cells in private Laboratories because there was a

Prohibition on uh using any federal funds to conduct research on a human

embryo so people like Jamie Thompson at the University of Wisconsin had a duplicate lab across the street where

everything in that lab from buying the pencils uh to everything else were paid for with private funds because if he had

conducted the same research on campus at the University of Wisconsin he would have violated um Federal RS so

fascinating little story behind a story but Science magazine in December 1999 um awarded stem cells the

Breakthrough of the year I'm not sure if you can see it very very clearly that

led to a number of other things Clinton asked the national bioethics advisory commission to work on this like oh my

God it also worked on Dolly minor matter a little Clon sheep but this became

something this was a big deal like a bigger deal for all of the arguments about what the benefits of stem cells

would be if properly used their potential was literally endless um they

were pluripotent or as the Brits say pluripotent which means that they can

evolve into any cell in the body I mean talk about a Wonder a Wonder machine

uh and back weight in with its own work and what I've highlighted uh to you here

you know one is the letter from to the president always fun to write a letter to the president like that's a neat

homework assignment make sure you don't have any spelling errors um but in uh inback as we called

it made a made an observation which I think is the first time that the public

really understood how difficult bioethics was when applied the public policy we said although wide agreement

exists that human embryo deserve respect and I put it in Red so

you wouldn't miss it as a form of human life there is disagreement both on the

form such respect should take and on the level of protection owed at different stages of embryonic development it took

a long time to negotiate 18 Commissioners to get that language that

was not just let's come up with something you know the phrase as a form

of human life what was challenging if you say it's a moral

person then you're taking a position if you say it's a blob of nothing you're

taking a moral position it's not a rock it's not a tree it's something

never mind the fact that you know tangential comment when NIH knew

that we were starting on this project they sent a number of interns off to the National Library of Medicine and said

can you give us a definition for when an embryo becomes a fetus so we know

because there are prohibitions on embryo research and there are different prohibitions on fetal tissue

transplantation research like what is this I'm sort of looking at Rich because

if anyone in the room would know about developmental biology and it would be him maybe there's other people in the room I don't know guess what they

couldn't find one why because this is life it it doesn't have a a date on

Thursday after six days and six hours it somehow transits from one thing to another

that's really hard to um to regulate so there are a lot of things

going on with this admission about the moral status of the human embryo which

wasn't just a philosophic question it had implications for regulation and federal funding meanwhile George Bush's

bioethics commission looked at this same topic a few years later and I'm going to say surprise

surprise but I don't mean that um humorously unsurprisingly they came to a

similar albeit slightly more dramatic conclusion which you also may have read

you know we still have a long way to go before stem cell-based therapies can be developed and made available for now

neither side to the debate seems close to persuading the other of the truth it

thinks it sees I mean that's epistemology in a bioethics paper the

truth the truth of like this is kind of fun if you're in the nerd game of trying

to unpack policy but it is a nightmare if you're trying to make a recommendation to the president of the

United States and Congress about what to do so that's sort of another chapter in

my journey uh that was that report was sent

on on uh on September 7th

1999 um and then you know a couple of years passed and then this happened well

what's the this the this is that the Lily endowment awarded Indiana University

School of Medicine 105 millionar the largest Grant in its

history I think I have that right bill it's 105 million maybe it's a big chunk um never

before given um as I say I was at L yesterday courtesy of of Matt relli and I got to if you haven't been there

there's a museum uh that you can see all about the family history of the lies and what they were all about and quite

interesting and one of the things we know is that Colonel Eli the founder was very specific about how the endowment

funds would be used it was to be used for public goods um religion and education and public works and libraries

and Community it was not to be about health now whether I haven't read a good

biography of him yet or having read a biography good or bad if you know of when I'd like to read it whether he was

thinking about the moral implications of a perceived conflict of interest if the money they made from drug development

should be used to fund drug I don't know but apparently the story and I'm happy to be corrected was we shouldn't do that

and yet they gave A1 $5 million two points why did they do it and why was it

105 like that seems like a weird number well they did it because and they're not here some of the Jedi Knights that I

showed you on the first slide people like miles brand and Craig braider and

Ora Pescovitz um I would say persuaded uh first time I've ever

used this sentence so it may not come out right persuaded the Lily endowment of the truth it thought it saw I try to

combine things of the value of investing in Indiana that this large Grant would

be it's not give us a bunch of money and you can you know design some medicines or you can pay for some medical students

or you can build some cool buildings it was a much larger Vision than that and I

say Bravo and many thanks to the Lily Endowment for doing that why was it5

Million some of you already know this story but in the early days um in fact

the beginning of the Genome Project when Jim Watson went to Congress and said if you give me $3

billion I will map and sequence I I will lead a program that will map and sequence the human genome in 10 years

bearing in mind that we didn't know how to map or sequence The genome when he said it but it was Jim Watson and he

said to Congress and they're like okay he said but there's one thing that

I do want to ask for I want to make sure that the ethical legal and social

implications of this work are also funded so I am requesting that

3% of the federal appropriation to the Genome Project go

to ethical legal and social implications not an amount 3% and of course in

virtually in every year except the Bush Administration the NIH appropriation went up so it's it was a brilliant um

strategy 3% of a larger number is more money every year it was adjusted to 5%

when Collins came in so the ELC program which Peter kindly reminded you that I led for three years was the steward of

this 5% of the NHGRI budget giving

extra meal grants so let's just say that um I was still working at NB when I

got a call from Craig Braer and said we're thinking of starting a center for bioethics and we'd like you to visit and

one of the ways we're thinking of funding it is through this large Indiana genomics

initiative that has this big grant that we want to submit to the Lily endowment what do you think about that and I said

I've got a cool idea why don't you ask them for 5% for bioethics there's a

history it's the Elsi program we'll try

that so it's $105 million because there was

100 million for the boring genomic stuff and there was five million for

bioethics okay and included this is the press release that listed bioethics as

one of the six key components of the initiative which is a non-trivial matter this wasn't we're going to do all these

cool things and then we're also going to make sure there's some ethics discussed this was a central component a key

component of the overall initiative and I think a lesson that was probably not I

I don't mean learned I don't think fully appreciated um over time as an Institutional strategy for how you embed

ethics into what you're doing yes you should have programs you should have centers for bioethics um I keep saying

Lily because Matt's sitting here you can have programs you can have committees you can have all kinds of things but the

risk is always if you if you Silo it into something over there in the corner

it will always be seen as that thing over there in the corner but the reason that those Jedi Knights were so

impressive is that whether they were in Liberal Arts or nursing or medicine or

law they all recognize the value proposition for IU and I'm forever

grateful for that um this is sort of a bit of a history again tyy May well Stan may as

well this is a could be a trivia test for the the folks in the room the bottom

right picture which may not look so good in the in the lights here is the ratush

uh VA Center which was the first home of the IU Center for bioethics we were in the

basement right next to where the weekly burning of biological materials

occurred every Tuesday it was disgusting um but we have had some nice

space um Charlie Clark was there to help us uh figure out our way around and then

eventually when the Magnificent hits building was built the center for bioethics enjoyed a spot on the third

floor again making a very important political statement we weren't just a little group we were on the same floor

as bio statistics maybe because we both started with bio I don't know but

Children's Health Services Research was there uh population uh omics was there

um a bunch of others and the idea was the common coffee pot on steroids you

know you're bumping into people who are doing Health Services Research and Pediatrics and Drug development and

biostats and you became unknown quantity you weren't those strange people over

there who I don't know run the IRB or something that is often so narrowly associated with what bioethics is

this was a research organization every bit as important and relevant built into

a grant same criteria for success by the way this is not a charity you got work

to do it allowed us to I didn't even know that rich was going to be here allowed us to have conversations with

others who said we're interested in that too why don't we recruit a pediatric bioethicist why don't we why don't we

try a number of things so it generated um as a case study a lot of activity I'm again using the rule of not

putting too many things on a PowerPoint slide but this is a a very um incomplete

list of some of the programs and projects that that initial uh Grant

supplemented by many other grants allowed the center for

bioethics to undertake um a few of them are personal favorites a reason that

relate more to the persons than the topics and I just want to share a few of

them with you uh now um if you think that biobanks is a new topic it's not um

you know universities and academic centers have been collecting stuff for

Millennia and in fact one of the first uh inback reports was on human biological materials in 1998 and did a

rough census and tried to figure out how many fridges there were in the world in the in the country and what was in them and of course nobody knew I mean why

would you even think that nobody knew its potential was because we had not unleashed the power of genomics to take

advantage of the stuff so a couple of interesting things happened I'm doing my

best not to get a little teary here but my colleague my late colleague Kim Quaid um was very instrumental um in our

Center for bioethics and helping us think through the uh the ethical issues in

biobanking um I apologize for the maybe you could see it but among the sort of

now so obvious it it's embarrassing to admit differences between the standard

ethical considerations in a clinical trial and the ethical issues in doing

research on collected material we sort of highlighted in very simple table

including the fact that you're if you're going to do you may be able to do research on on stuff taken from

someone many many years or decades into the future after they're dead it completely flipped the research ethics

paradigm on its head what's a human subject never mind participant what does it mean to enroll in a study when you're

just allowing diagnostic material to stand collected um can you withdraw from

a study you know we had a Charming analogy to the song Hotel California you

know you can check out any time you like but you can never leave you know once once stuff is in the bank whether the

physical material is there and the data has been disseminated we don't know what the

concept of withdrawal means it's it's a non-t everything changed so genomics

shifted research ethics paradigms it shifted clinical paradigms and Kim certainly wasn't the only people um

another sort of friend of the family that would probably be familiar only to the older folks in the room this is a

picture of Monroe peacock who headed the gcrc uh we had I would say

some entertaining discussions about building the biobank here at

IU um where our IRB just didn't get it

there's more to that story um Jill will see the next slide that proves that this wasn't a oneshot deal uh but the idea of

going to an IRB and saying we don't want to build a biobank they're like cool what's the research question we don't

have a research question okay Who Are You recruiting don't know yet they

going to be people that come through maybe they come through a clinic and they provide some diagnostic

material maybe they come involuntarily want to participate I don't know well what are you going to be studying not

sure so when does the study start it doesn't really start when does it finish can't tell you that either can we have

approval like are you crazy we don't know how to talk we don't know how to discuss this and people like Monroe if

you those of you who knew him I mean he was a he didn't take those kinds of

rejections lightly and in a way he started said right I need to bring in the ethics guys and see if we can

convince them like maybe they have some magic ethics words that they you know

say and everyone lies down and says of course we'll do whatever you want hardly but we eventually sort of I think we're

able to Pivot the IRB this was not a One-Shot deal and it wasn't their fault this was common to irbs Across the in

fact around the world irbs built on a Model designed to protect human subjects

never mind parti to protect human subjects from harm was the model research was

dangerous our job is to only allow people into a study when it's so obvious

that they will not be harmed and they maybe they'll benefit but we can't promise them that that's called

treatment that's our model that's our philosophic mindset that lasted from

about 1974 when the national commission produced The Belmont report that led to the RS that led to the irbs that was UN

changed for probably 25 years so it's a big ship to try sorry a

big sort of ship to try and pivot on its on its place uh but it's because of

people like Monroe and Kim that we were able to educate not scold not embarrass

but there's a new world out there the right side of the slide you'll see another dear friend Hal Brosme um who

was asked pal and I were asked at that time one of I think us well the

world's most uh impressive scientist certainly that I've uh ever met um who was asked

by Dean Braider with me to produce a report of the of a task force for

establishing an adult stem cell research center now we don't have to go into the

the genomics or physiology of what adult stem cells are but this was not a stem cell taken from an embryo had to be

destroyed you know skin cell you were able to do a lot of other kinds of things with stem cells that don't

involve the moral quandry of embryos or fetuses and you can understand not just because we're in Indiana everybody was

concerned about how one treats this form of human life doesn't matter where you

are it makes no sense to try and do something that would be offensive undignified

unnecessary um a waste like why when and there's another form or another um

resource that would provide maybe not complete but certainly sufficient

research um here I can say material to do the work so Hal took time out of um

his important work with hetic stem cells and uh we wrote a report a report got

read um and uh and work continued so I'm very sort of intrigued by and I put

their picture here I mean I tagged along and I'm not being uh you know falsely modest this required the leadership of

the medical and scientific Community this was not a bioethics um Don kot like

activity I'm coming in and you must and here's my windmill it was it had to almost come from them right kind of The

Sweet Spot was it's their idea that will that will help things

um meanwhile um

I was introduced to some pretty impressive people one of whom is here in the room Jill um and something that I

didn't even understand when it first started like I didn't get this thing I

knew the history um you know that that Connie and Su Clair and others had

related about the NCI meeting in I forget the year 19 I don't know sometime

back in the day when uh it was stated that you know the biggest impediment and correct me if I'm wrong

Jill but one of the main impediments to uh to curing breast cancer is we don't know the ideology of normal breast

tissue like we don't know what normal is so if we don't know what normal is we don't know what is not normal or abnormal

is so followed by well how are you ever going to get that like how are you gonna get normal breast tissue like I guess

we're gonna have a problem with cancer because no woman is going to want to voluntarily allow 14 gauge needle to be

stuck into them for non-diagnostic like that's ridiculous gentlemen imagine a

equivalent yeah enough said um boy was I wrong well I guess NCI

was wrong because of the leadership of these folks and many others who basically said you want to bet we

can't get women to voluntarily agree to donate tissue watch us I'm not qualified

to give the entire history but what I can say is that in discussions that a

number of us were invited into um with the same kind of Monroe

peacock biobank feel to it it's we've

got this idea we want to collect specimens from women we may use the race

um which is a great place educate and allow women to make a decision if they'd like to do this um

now it is research there's no question it's research so guess what IRB we're coming

back to have another conversation with you if you thought the first one was hard this one is like there's living

people walking around who are going to be asked if they wish to do this I wish

I could tell a longer story but what I will what I will say because the story is legendary and I've tried to do my

best deal whenever I talk about this around the world to highlight what is particularly unique about this which was

another pivot point in not just um genetics because that's certainly one

part of it but in research ethics generally our view was again protect

produce a consent form list a bunch of things try and discourage people you don't want everybody to agree that would

almost sound like inducement because in bioethics you almost think that if too many people agree to something you're

not giving them sufficient information we don't know what that number is but everyone shouldn't agree to participate

in research but we don't know how many fewer than everyone makes it look like

we've done a pretty good job of scaring certain people and uh incentivizing certain people but to say that this took

off is a understatement um including this again these are stories that I remember of of

a volunteer saying um I don't really need the consent form like I want to give I want to give

of myself reasons that had nothing to do with oh research is very important this sort of

ephemeral Global idea about the importance of research is I'm doing this because I had a mother sister daughter

or I know someone who had a mother sister daughter and what really like dropped me to tears was seeing the

journal entries that they would or not Journal I guess it was like a journal entry this is why I'm doing this so it

was almost like the reverse I'm telling you why I want to do this not you giving

me information and I'm going to agree to come into your study the goal was to

fill up this bank as quickly as possible and deplete it as quickly as possible

this wasn't about commercialization it was get the stuff out to the world as quickly as possible we want to cure

breast cancer my friend Peter singer who was until recently the uh the special

adviser to uh to Dr. Tedris at who has been writing some nice blogs lately and

one of them is about um how the SGS are just not really working the sustainable

development goals are just we're not getting there and Peter has said his new model is we forget sdgs we should do

gsds get done like enough with the planning enough with the thinking and

the meetings and the photo ops and let's have a meeting to talk about the meeting and the next meeting it's like we got

stuff to do let's do it and in a way Coman for me way before any of this

model was I know it's being recorded and if those online are offended by me saying like too bad like Coman was

getting done thank you uh before other people were it's a very

interesting model um other things we did at the center for bioethics um you don't

have to read all these but we were talking about predictive Health we had a program that and among the admitted

failures uh that I will own up to is I really suck at coming up with acronyms I

know it's a special skill that tyranny's got and I'm sure others I just can't do

it so we camp with thing called predictive Health ethics research and called it predictor it's

like anyway uh Fairbanks gave us a chunk of money we started to do work on topics

back then which are the same topics today just with different

emphasis um another kind of tearjerker here um personalized medicine Institute

that our dear friend David Flockhart started um that's Barbara Evans our friend uh who was with us for a few

years and then moved to Houston and University of Florida one of the world's polymaths in engineering law uh ethics

and regulation uh I just have a couple of screenshots and I included Peter not because he introduced me but Peter was a

leader before anyone else was and thinking about how to take information um about

to take data and apply it to Patient Care not just the evidence-based medicine stuff that's Charming but to

really look at how do people understand risk great topic we don't spend enough

time thinking about it if you're wondering why there's a refrigerator on the slide the reason is that Barbara

came up with the best analogy of all time and ident recognized after doing a

fairly good pharmacoeconomic analysis that only about two-thirds of

drugs work as planned like for the thing that they should happen and among the

third that don't a bunch just like they don't work like okay they don't work a

much smaller version of that about 7% actually harm and then a little tiny

part like kill you now that's with the math at that time was you know many

hundreds of millions of dollars are being spent on drugs that actually don't work now never mind the ones that that

harm but if you just look at the ones that harm 7% is a big number and the analogy became if 7% of refrigerators

failed wouldn't you have a wouldn't you be concerned about those refrigerators I mean yes we have warranties so you can

get your refrigerator fixed or maybe buy a new refrigerator if it's a lemon but

7% is a lot never mind if they fell over and killed you that's a different problem so so Barbara came up with quite

an inventive Le new legal theory about what it would mean if medicine

guaranteed that what they were doing would work that was the promise of personalized medicine right drug right

time right person right reason what if we move that one step further and said I'm going to test you first to make sure

that you do respond to this then I'm going to guarantee you that's so bizarre

in medicine and nursing and health we would never utter those words guarantee those are some of the experimental ideas

we worked on um all of the only point of this slide is to say that there are a few of

us who started to get a little nervous about all the genomic hype like you know we're saying it's

great there's going to be cures they're coming they're on their way where are they this was a paper 10 years uh

written 10 years after that White House Event where some colleagues of mine and I said maybe we should pump the brakes a

little like because if the public starts to get too excited and then we don't deliver there'll be a a real Whiplash

people will with draw their trust stop supporting signs and we don't want that to

happen okay just quickly on to the Future and we can have some uh if we

have time for a couple of questions pick your favorite quote here one is from our friend Howard uh

Brody who wrote a book that's on the Shelf in the center for bioethics who said back in 2009 I don't think

bioethics should spend much time thinking about genetics like you know what more is there to say read the book

you'll see um you know do we need to use bioethics anymore it's pretty much a regulatory problem like don't worry

about it the better quote of course is the future ain't what it used to be which is Yogi Vera in which case this

slide is just simply meant to capture a selection of what has been happening and

I have three slides I'll just let's go through them very quickly first of all genomics is big business and that's not

even a really good slide it's one of 50,000 slides that you could pick that shows lots of people are spending more

money and there's a big payoff at the end the top right is showing what we all

know not just about not only about um about Mo's law but we know how genomic

large salale sequencing and whole genome sequencing the price is going down and down and down and you know eventually

it'll hit a number like buying licorice in the store but that is a non-trivial

matter when the price of doing something becomes not only uh a non-issue it sort

of opens up uh the world to not I don't mean Bad actors but it just democratizes

much more quite an interesting phenomenon the left bottom is the andral genome story which is quite interesting

and the right um is the extinct um African gazelle that has just been uh

whose genome has just been sequence bringing back extin species these two sort of remind me of um entertaining

bioethics kind of what happened with 23 and me and a few of the other otc's um

that's interesting that's curious not sure what we're going to do with that but interesting um lots of other things

going on not enough time to go through all of them uh biod digital convergence

is my favorite which is where you start to actually um combined

genomes um of human and animal there's an awful lot of work going on at the oecd and elsewhere about the convergence

of many Technologies it's no longer siloed Technologies crisper genan Drive Public

Health genomics excuse me polygenic risk scores synthetic biology the list goes

on um Bill Tierney and I just came back from from pbla in

Mexico where the day after I returned nature spent a good chunk of their

issue talking about the Mexi Mexican genome and Mexican genomics this is simply

a uh a photo of something that represents something much larger and

that countries are now engaged in this as a matter of domestic um S&T and R&D

Mexico Estonia Iceland this is no longer the small group of four or five countries that mapped and sequence the

genome the US the UK Japan and a few a couple of others this is now a global

activity um I'm very proud of the fact that Canada spent um some very important

intellectual Capital first during SARS and then during uh Co 19 to map and sequence first the Corona virus and SARS

and then the host and virus sequence for many of the um the CO2

um uh genomes uh done by collaboration cooperation lowering the barrier to peer

review lowering the barriers to uh to funding like how much do you need when

can we get this done so it's interesting how science can serve as a um a mover or

a lowering of barriers that Society has put up and I just put the public

health genomics uh paper uh screenshot here because let us not forget that this

isn't simply about clinical care there's a way of implicating genomics in in in

Public Health um I don't need to say anything more about this topic that's why I made it as big as I could it's

everything I had a fun chat at L yesterday tell you more about it another

time um and then I'll just remind you that because my journey has been one

that spent a lot of time in policy land um sort of out of the clinic even out of

the University this is my that should say tools of go of policy and governance

have EV involved um again massive toolbox more things there more things

than exist on this slide and I happen to believe that the choice of

the right tool at the right time for the right reason is as much a moral issue as

which drug you should be uh ascribing uh prescribing and lots more to be said

about that we've watched how uh Gene editing is the subject of one of those and I'm

going to close with um with this reminder which may be just a little too

cute by half but I I've become convinced this a a screenshot of a some work that

a friend of mine Alesandro Blime from uh eth in Zurich and I've been working on

that kind of reminds us that some of this has nothing to do with science at all you know how we spend money on

genomics how we spend money on this or that it's actually about social policy

and the problem with social policy decisions is that we don't even agree on what we agree on particularly in in you

know what we call liberal democracies because we don't have a good this gets back to your deliberation stuff

Peter we just don't have good ways of deciding how to decide when people disagree uh about priorities so since

we're talking about genomics this is what I call my IU I hope you don't mind

the effort to construct a new omic um you will see many of the same faces uh

that I mentioned earlier you should know that I saw Pat Lair at the airport when I came here on the way to DAR for a

meeting he arrived safely in case you're wondering and I showed in this slide I hope he's listening to this talk I

showed him the slide I said Pat I really wanted you to know that you matter a lot to me and first thing he said to me is

how come my picture is so small can you make my P and if you know Pat Lair can

you make my picture bigger no actually can you get rid of all the other pictures and just just put my picture

there um Rich if I knew you were coming your picture would be here in a in a hall of Honor I won't go through all the

names but um these are people that have helped me with my own journey

and then we don't have time but the name of this topic was of this lecture was

where have the genomics gone or where would where would where will genomics go

in the future and if we had time I was going to leave a sing along um to where have all the flowers gone I'll just

leave that up there and you can hum it in your own in your own mind thank you very

much so you need to go please go you need to stay please

stay yeah sorry I went a bit longer but that shouldn't have surprised anybody Rob

cats re I don't know repeat the question when

there are good question I would love to have something

that's the only question we got thank you Peter something about you didn't talking about um regulation height you

didn't mention Co which may have heard about is this little thing that happened the last couple years how do your view

of ethics and think about science changed if at all can you repeat that question uh how has Covid changed if it

has my view about ethics and Science and how he respond and the answer is in some

ways quite a bit and in other ways not so much for the reason that I said earlier about the lesson learn problem

Covid uh on the one hand can be seen as yet another Public Health Emergency of international concern we've had a bunch

of them we've actually been through a bunch of pandemics this is not the first one we've ever seen and somehow

magically we either have amnesia um or we truly don't get it so that's one one

part the thing that I I believe that Co has exposed

in bioethics turn to me turn to me

saying without looking devilish good he's nothing if not subtle

right um it's exposed what I would say has been uh well maybe a well-kept

secret not sure in bioethics and this is where I'm going to go and I don't mind if it's sort of

offend some of my colleagues in the field we like congratulating ourselves

about how smart we are and our ability to figure out uh why this problem is a

problem we're very good at being house inspectors we can find a flaw in your argument we can find a weakness we can

find a wormhole we can sometimes find Solutions and we do it because we're not allowed to touch anything we're not

those of us who are not clinicians so we have to use our our head and in the course of that that on the one hand

legitimacy I'm in the room like I'm one of the six components I'm not just Furniture so my contribution is my brain

and my thinking and it needs to be received I don't think we have been as

Nimble in the field of bioethics as we should be or could be and what coid has

done for me at least is it has exposed some of the weaknesses not only in the

broad field of bioethics but in the way that it can most effectively engage in help policy what's an

example well in Canada the vast majority of people who died from Covid died in nursing homes nursing homes are one of

the areas that are not regulated under Canadian Health policy we have you think

we have National healthcare we don't we actually have a federal government that provides a set of standards that

each of the 10 provinces and the three territories are expected to follow if they want to get a bit of federal

funding but we really have 13 Health Care Systems we don't have 2,000 of them

but we have 13 um they don't all think about Healthcare in the same way they decide

how they're going to spend their provincial budgets beyond the requirements of ensuring Equitable

access to care and what I think the Covid story exposed for us was how you know it's too

cute to say social justice issues but how issues of community um and access to a Health

Care system that claims that it is helping didn't work like we said oh

that's terrible that all these older people died in nursing homes that was really terrible we should do something

about that and I think that the way you care for the most vulnerable in your

community is evidence of what your moral concern is generally and I can't think of people more vulnerable or more in

need of our care hope respect than those who are in uh those

facilities let alone our indigenous population and we have three large kinds

of groups we have First Nations people we have met and we have Inuit um who

are also among the least well-off I mean there's still at last count maybe two

dozen boil water advisories in Canada on

on reserves you call them reservation we call them Reserves two more questions with short answers Eric

okay have a quick question I'll try and make it a quick answer apparently so I

thought the way that you ended was really powerful with the idea with the

problem of and the co question made me think kind of along these lines too and the

difference between say Public Health ethics and ethics in a clinic where you

have more of a chance to tailor individual care to the individual values

um but when you're working at a public or public health or national level you don't have that same power one thing I

would love to hear your thoughts on is I've noticed a shift in the way that people are think know genetics which as

you mentioned throughout your entire thought there are still like very pluralistic attitudes towards how people

should approach genetic medicine since that is individual but because policies of faing G policies

about mandatory testing yeah or analysis um affect a much larger population how

do you where do you see that going how do you that so it's a great and I will keep it brief repeat it though which is

also I do because we don't have a microphone on okay

um such a good question um how do you how do I see the connection if at all

between the way that genetics is both both a clinical field and

a community field in the sense that you can tailor medicines to people but you're also part of a population and and

public health issues if I didn't do that so well I can still give the answer that sounds like I mean I heard what you said

but I'm not really good at um using getting short phrases for a grant and

I'm really not good at summarizing apparently and by the way are you humming in the back of your mind I

really hope you're trying to do this because I spent a lot of time working on this um the short answer

is I think that the public health ethics um area of scholarship and

application is the most needy of some

disruption because we know that the public doesn't understand Public Health

like they don't get it when it works perfectly it's invisible like the water

is clean there is no salmonella in the salad bars

and um and people and everyone's been vaccinated and it's fine and

unfortunately public health is one of those things that you notice it when it's not working and I think that's a a

non-trivial problem with the translation of its value to the public it's what led

in many ways and Canada was not immune to the misinformation and disinformation campaign that CCA documented and many

other people that would have lived numbers that would have lived if they had been

vaccinated and not because they weren't able to be but they mistakenly believed

something that they read that led them to conclude that they shouldn't get vaccinated wasn't a rational Choice some

people may even wish to choose not to do so okay I mean I'm not a big fan of

making that decision but for those thousands and we had thousands we had a

great uptake you know almost all Canadians had three shots good far better than us data but the data of who

didn't and why is troubling and I think it's a huge um opportunity for

bioethics and policy to get together I don't want to be really controversial on my last comment but honestly maybe we

should stop calling it bioethics I mean because I think that scares people okay we

stop talk on the other hand

or okay how do I do

the let me do Matt then Matt I think there could be some tension

between how genomics is applied and concept personalized medicine I think we

see so far is things like in Mexico or by race or by some other grouping we

investigate genomic and we say oh well there's a disproportionate amount of something in

in this population and then we draw the conclusion that it applies to that population but it's really probably only

40% of that population or something like that so then when you make the

implications of that you know 60% are going to not get the right medicine for them or even if it's flipflop a huge

chunk how do we balance that se yeah and I'll do the real short

version and honestly we've done work on this with colleagues in the UK

on the words that we use actually matter there is a difference when you ask

people what they know about population Health versus Public Health it sounds strange complete these are two different

worlds for them and legitimately they are but it's like saying experiment

versus research causes very different reactions when you ask people whether

they support or that's at the public level I think the same thing is happening with all not all do respect

because it's not about you to our politicians who really don't understand in many instances the Nuance of what the

goals of science might be where on the one hand the idea of curiosity-driven research which is absolutely critical um

is really fight appears to be fighting with um outcomes research show me what you're going to do show how it's going

to help including the much appreciated case that was made to the Lily endowment

which is yes this is about research but it's really more about how we're going to help Hoosiers like that's a very both

are true and I think it's the ability to hold two truths at the same time uh that

will help make that case but I can tell you that that it's so easy to fall back I can tell you I feel that it's easy to

fall back into the old rhetoric of um identifying people with disease or

geography with disease I mean remember what happened with AIDS in the very early years if you are from Haiti like

what so we have a we have an old set of tools in

discrimination um in human rights that we probably need to dust off a little

bit the closer we get into the public health population Health Public

Health genomics population when we start going there you know the autonomy flag

should just sort of be set down for a moment just leave it on the side and start thinking about what Collective

decision-making looks like is that that's perfect great thank you so much any questions come and grab Eric of

course and uh we'll thank you all for

coming