

"THE HERITAGE"

Giorgio Mottola

Collaborators: Alessia Marzi and Carla Rumor

Camera: Davide Fonda and Davide Rinaldi

SIGFRIDO RANUCCI IN THE STUDIO

The main topic this evening is dedicated to our DNA, our genetic heritage. DNA contains information about how we are, our past, our future and the possibility of suffering from diseases. But the problem is: who does this heritage of knowledge belong to? If it were to leave the laboratories and end up in the hands of businessmen, advertisers and politicians, what would the impact be? It may sound like science fiction but it's been a reality for 10 years. With great secrecy, Google is setting up the largest genetic bank in the world. Multinationals are competing to get their hands on our genetic heritage, even if only to boost their quotations on the stock exchange. In short, it is a precious commodity and we should worry about anyone seeking to steal it. Our Giorgio Mottola underwent DNA testing and all kinds of things emerged ...

GIORGIO MOTTOLA OFF-SCREEN

In this part of Sardinia called Ogliastra, where the inland mountains slope down into the sea, local inhabitants have developed an enviable trait.

GIORGIO MOTTOLA

Madam, may I ask how old you are?

ROSA SECCI

102!

GIORGIO MOTTOLA

How did you manage to live so long? What's the secret for such a long life?

ROSA SECCI

Boh ...

GIORGIO MOTTOLA

... what do you eat?

ROSA SECCI

I eat like everyone else...

GIORGIO MOTTOLA

The same as everyone else?

ROSA SECCI

Nothing different.

GIORGIO MOTTOLA OFF-SCREEN

Rosa sadly died a few days ago. Yet the true secret of her longevity and that of other inhabitants in the Ogliastra area is hidden in their DNA - that in fact is so precious it has been put in a bank.

GIORGIO MOTTOLA

What we can see behind us is a bank?

DEBORA PARRACCIANI - CUSTODIAN, OGLIASTRA GENETIC BANK

Yes, it is a genetic bank of inestimable value because it does not contain money but biological material.

GIORGIO MOTTOLA OFF-SCREEN

This genetic bank holds the DNA of 13,000 inhabitants of Ogliastra in a total of 250,000 test tubes. A genetic heritage so unique in the world that last year it was literally a steal.

PIERGIORGIO LORRAI - PRESIDENT OF THE GENOS PARK

It was about half past ten in the evening, in August, when Mrs. Parraciani called: "They've stolen our DNA". That was the true definition. Our faces utterly paled.

GIORGIO MOTTOLA OFF-SCREEN

Since this the first theft of DNA in history, the news immediately travelled around the world. The Carabinieri the the Prosecutor's Office in Lanusei launched an investigation.

PIERGIORGIO LORRAI - PRESIDENT OF THE GENOS PARK

Then the samples came to light again. It was just a researcher who told the press and the Carabinieri that he had merely moved them.

GIORGIO MOTTOLA

And who was this researcher who moved them?

PIERGIORGIO LORRAI - PRESIDENT OF THE GENOS PARK

Dr. Pirastu.

GIORGIO MOTTOLA

Pirastu is not just any old researcher ...

PIERGIORGIO LORRAI - PRESIDENT OF THE GENOS PARK

Dr. Pirastu was the head of the CNR.

GIORGIO MOTTOLA OFF-SCREEN

The former director of the CNR Genetic Institute in Sardinia, Mario Pirastu, is the creator of the Ogliastra genetic bank. To finance the project in 2000, together with Renato Soru, he founded the Shardna company. Yet when the samples disappeared, Pirastu was on the point of retiring and no longer had access to the database.

GIORGIO MOTTOLA

If you were about to retire, then why did you take these 13,000 DNA samples without saying anything to anyone?

MARIO PIRASTU - FORMER DIRECTOR OF THE GENETIC INSTITUTE OF POPULATIONS - CNR SARDINIA:

No, even this is not true. Ehhh ... because I moved these samples three years earlier.

GIORGIO MOTTOLA

Why did you not immediately say that you had the samples they were looking for? Why did you wait for such a long time ...

MARIO PIRASTU - FORMER DIRECTOR OF THE GENETIC INSTITUTE OF POPULATIONS - CNR SARDINIA:

Not at all, I waited 3 days.

GIORGIO MOTTOLA

In truth, almost a month went by ...

MARIO PIRASTU - FORMER DIRECTOR OF THE GENETIC INSTITUTE OF POPULATIONS - CNR SARDINIA:

No, no ... prove it.

GIORGIO MOTTOLA

Among other things, it was only after the Carabinieri came to look for you ...

MARIO PIRASTU - FORMER DIRECTOR OF THE GENETIC INSTITUTE OF POPULATIONS - CNR SARDINIA:

If you turn the camera off, I will tell explain ...

GIORGIO MOTTOLA

Ok, sure.

GIORGIO MOTTOLA OFF-SCREEN

For the time being, the Prosecutor's Office in Lanusei investigating him for aggravated theft does not believe in his explanations. The disappearance of the samples was reported on 13 August but Pirastu discolsed that he came into their possession only a month later. And the mystery is even thicker because a few weeks before the alleged theft, the entire genetic bank had been put up for sale. Shardna went bankrupt and, exactly a month before the disappearance of the tubes, all the DNA samples were bought at auction by a British company, Tiziana Life Sciences.

GIORGIO MOTTOLA

Some say that you are behind Tiziana, behind this purchase by Tiziana.

MARIO PIRASTU - FORMER DIRECTOR OF THE GENETIC INSTITUTE OF POPULATIONS - CNR SARDINIA:

This is of course quite untrue. I challenge anyone to prove otherwise.

GIORGIO MOTTOLA

You also took part in a public conference sponsoring Tiziana's operation.

MARIO PIRASTU - FORMER DIRECTOR OF THE GENETIC INSTITUTE OF POPULATIONS - CNR SARDINIA:

Yes, on behalf of the CNR, because I am personally keen for this research to go ahead.

GIORGIO MOTTOLA OFF-SCREEN

Yet today everything is at a standstill because the prosecutor has seized the DNA, following a legal dispute brought about by the donors themselves about who exactly owns it.

DNA DONOR

They sold it, it was something they shouldn't have done.

GIORGIO MOTTOLA

If you had known that your DNA would have been sold to an English company, would you have donated it?

DNA DONOR

No, no, no.

GIORGIO MOTTOLA

Would you have donated your DNA?

DNA DONOR

I don't know. Probably not. If they sold it, it means they did so for profit.

GIORGIO MOTTOLA OFF-SCREEN

The new owner of Ogliastro DNA - "Tiziana Science Life" - is based in this building in central London. It purchased the entire genetic bank after paying 258,000 euros - yet in just three days after the purchase, its equity on the stock exchange earned about 50 million euros.

GIORGIO MOTTOLA

Is it possible to buy and sell DNA in Italy?

ANTONELLO SORO - PRESIDENT OF THE PRIVACY AUTHORITY

Trade in the human body, genomes and biological samples is not allowed.

GIORGIO MOTTOLA

Yet an English company purchased the DNA of 13,000 Sardinians ...

ANTONELLO SORO - PRESIDENT OF THE PRIVACY AUTHORITY

But there is no ownership of a bio-bank. There exists only the ownership of research performed with that data.

GIORGIO MOTTOLA

Under what conditions can "Tiziana Science Life" use that genetic bank?

ANTONELLO SORO - PRESIDENT OF THE PRIVACY AUTHORITY

For an explicit legal disposition or because it has the authorization of the guarantor.

GIORGIO MOTTOLA

And has "Tiziana Science Life" asked you for such authorization so far?

ANTONELLO SORO - PRESIDENT OF THE PRIVACY AUTHORITY

No. We have had no direct contacts with "Tiziana Life" yet. I must say ... it's a singular attitude even of ... of non-transparency.

GIUSEPPE TESTA - MOLECULAR BIOLOGIST AND BIO-ETHICIST, IEO UNIVERSITY OF MILAN

By now, DNA has become information. And it is one of the richest, most precious sources of information ... The word "biobank", that is ... because we have started to call them biobanks rather than bio-libraries, for example, clearly explains such great commercial interest.

GIORGIO MOTTOLA OFF-SCREEN

Interest in DNA is global and the multinationals have thrown themselves in headlong. But just a moment: we've been talking about it for over six minutes. But how many people can correctly answer the question "What is DNA?".

MAN

DNA is effectively ... let's say it is ... the word doesn't come to mind ...

MAN

Thermonucleric acid, no?

WOMAN

More or less ... dysoxy...

MAN

Dysoxy ... ribo ... ribbonucleric ... right?

MAN

Eh ... how can we explain it ...

MAN

It's the set of ... just a moment, eh

GIORGIO MOTTOLA OFF-SCREEN

An Italian scientist selected by former President Obama as one of the young talents in the field of genetics will explain it for us.

RICCARDO SABATINI - SCIENTIST AND ENTREPRENEUR

Fundamentally, it's a huge package of molecules. There are four that, once assembled correctly, build the instruction manual for your cells, to assemble who and what you are. By assembling these letters, you can build a flower, you can build a plant, you can build an animal, you can build a human being. Just imagine if you wanted to replicate this process and be able to do so using a 3D printer and wanted to take atom by atom, and assemble a new-born child, the list of these atoms, if you wanted to save it on a USB stick, you would need enough USB sticks to fill about 10 thousand "Titanics". This is what ... nature has managed to squeeze into this process, into a microscopic molecule package, a fraction of your hair; it took four billion years ... it's the most sophisticated software that a ... even a nerd can find.

GIORGIO MOTTOLA OFF-SCREEN

Although it was discovered more than sixty years ago, it was not until 2000 thaty DNA was viewed with different eyes, when the then-president of the United States, Bill Clinton, made this announcement to the world.

BILL CLINTON - PRESIDENT OF THE UNITED STATES 1993-2001

We're here to celebrate the completion of the first human genome. Without doubt, this is the most important, most wondrous map ever produced by humankind.

We're here to celebrate the completion of the first human genome. Without doubt, this is the most important, most wondrous map ever produced by humankind.

RICCARDO SABATINI - SCIENTIST AND ENTREPRENEUR

At the beginning of the new millennium, an exceptional revolution occurred: we became the first species on the planet, and probably the first species in the entire Milky Way, to have access to its own source code. That is to say, we can read the

instruction manual which was used to make us. And this is the revolution that will forever change medicine and all access to our biological interactions. This is the millennium revolution.

GIORGIO MOTTOLA OFF-SCREEN

A revolution that is transforming science, medicine and our everyday lives. Yet we are still only at the beginning of an epoch-making change.

SERGIO PISTOI - BIOLOGIST AND WRITER

The costs of genetic technologies are falling significantly and it is consequently moving out of laboratories and insiders literally into our own homes.

YOUTUBER

Hi guys, welcome to this new video ..

GIORGIO MOTTOLA OFF-SCREEN

A genetic test today costs less than 200 euros and can be conveniently ordered online.

YOUTUBER

... some time ago, I sent for a DNA test.

GEEKSPRITZ - YOUTUBER

And now I'm going to reveal the results of the DNA test.

GIORGIO MOTTOLA OFF-SCREEN

This is the 23andMe test, one of the most popular in the world. We decided to try it out ourselves. After placing the order online, the kit is delivered directly to your home. Here it is: instructions, phial and sachets to seal. Fill the test tube with saliva, seal it and send the kit back to 23andMe.

After two months, the results are sent to us via e-mail. The test shows that my genetic characteristics are similar to those of Queen Marie Antoinette and Thomas Jefferson. But above all, I find out that I am only 50% Italian. The other part of my genes is divided between North-Africa, the Middle East and 0.1% Ashkenazi Jewish.

STEFANO GUSTINCICH - DIRECTOR OF LIFE SCIENCE-ITALIAN INSTITUTE OF TECHNOLOGY

I would say that this analysis by 23andMe tells you about the potpourri of various genomes that your family ancestors and you through your ancestors has collected over the centuries.

GIORGIO MOTTOLA OFF-SCREEN

Yet the 23andme test also told me something about my health. According to these results, I am intolerant to lactose, I handle alcohol well but absorb fats badly and I have no risk of Parkinson's or Alzheimer's. But I nevertheless have a worrying genetic variant: I am at risk of maculopathy. In a few years' time, I could become completely blind.

GIORGIO MOTTOLA

Professor, reassure me: am I going to become blind?

STEFANO GUSTINCICH - DIRECTOR OF LIFE SCIENCE-ITALIAN INSTITUTE OF TECHNOLOGY

I would say not, not the least because the variant found does not increase the risk of macula degeneration. So I honestly do not understand why it was included in your analysis.

GIORGIO MOTTOLA OFF-SCREEN

How reliable is the 23andMe health report?

STEFANO GUSTINCICH - DIRECTOR OF LIFE SCIENCE-ITALIAN INSTITUTE OF TECHNOLOGY

Looking at it, I was rather puzzled.

GIORGIO MOTTOLA OFF-SCREEN

And the Food and Drug Administration (FDA) was also puzzled, since in 2013 it suspended the sale of the 23andMe kit. The block was then lifted in the US but some restrictions remained in Europe and Italy, where the American company only provides genealogical information.

ANTONELLO SORO - PRESIDENT OF THE PRIVACY AUTHORITY

I must say this is a genuine problem. On the one hand, there is a profile of medical-scientific reliability for the result of these tests; on the other hand, measures are needed to protect personal data.

SERGIO PISTOI - BIOLOGIST AND WRITER

The legislator and the experts are discussing whether it is right or not that people can access their genetic profiles and DNA tests on the Internet. Yet before this discussion may even be over, we will have a device at home capable of reading our DNA without even passing through Internet.

GIORGIO MOTTOLA OFF-SCREEN

While they are debating matters, some people are already publishing their genetic information online. It is the new social dimension involving DNA launched on the world market by 23andMe that allows us to discover other people in the world having DNA similar to our own.

SERGIO PISTOI - BIOLOGIST AND WRITER

This is actually what I would call the Facebook of my DNA. One of the first results is this bulletin board where you can see profiles of people with names, surnames, and often even photos, just as on Facebook. And there is a column where I am shown the degree of kinship I share with these people calculated on the basis on comparisons of our DNA.

GIORGIO MOTTOLA OFF-SCREEN

But isn't this rather scary? I mean, it rather looks like mass genetic profiling.

SERGIO PISTOI - BIOLOGIST AND WRITER

It's genetic profiling that I ... I voluntarily accepted.

HELEN WALLACE - BIOLOGIST - DIRECTOR GENEWATCH

Your DNA is like a fingerprint that can be used to profile you, identify who your family is and acquire private information such that about your health. We should be very careful over sharing our DNA online. Not only for ourselves but also for our family members.

GIORGIO MOTTOLA OFF-SCREEN

So, you believe it is preferable not to publish your DNA online?

HELEN WALLACE - BIOLOGIST - DIRECTOR GENEWATCH

I would advise your viewers not to do so. Take the DNA test. But to understand what use will be made of your data, read the terms and conditions very carefully.

GIORGIO MOTTOLA OFF-SCREEN

And this is precisely where the problem lies. "23&Me" asks us to sign a waiver that is a full-scale contract pages and pages and pages long. Understanding what exactly they will do with our DNA is very complicated.

STEFANO GUSTINCICH - DIRECTOR OF LIFE SCIENCE-ITALIAN INSTITUTE OF TECHNOLOGY

Their business model is brilliant, if you think about it. You pay to expand the proprietary information database operated by "23&Me" which can then use this information to generate profits through commercial agreements.

GIORGIO MOTTOLA

So, I thought I was receiving data but in actual fact I gave data to them.

STEFANO GUSTINCICH - DIRECTOR OF LIFE SCIENCE-ITALIAN INSTITUTE OF TECHNOLOGY

Yes, and not only that, You also paid for the privilege.

GIORGIO MOTTOLA OFF-SCREEN

Thanks to data provided by its customers, in 2015 alone "23&Me" earned 50 million dollars from sharing just a part of its database with pharmaceutical giant Genentech. With over one million DNAs collected, "23&Me" is currently the largest genetic bank in the world. And who is the lucky owner of all this data?

SIGFRIDO RANUCCI IN THE STUDIO

"23&me" was founded in 2006 by Anne Wojcicki, then wife of Sergey Brin, the founding father of Google, who in turn has an important equity holding in "23&me". THERE are also Yuri Milner, the Russian magnate, who in turn has equity holdings in Facebook, Twitter and Airbnb. But what are these web giants doing in the field of genetics? First of all, they were the first to understand that we are the product and thanks to the information they have in their powerful databases they know who we are, where we connect, what we buy, what we like to eat, what our passions are and even our political sympathies. So, they put all this information together with our genetic heritage, which we made available ourselves by doing the tests and paying for them as well. If all goes well, they sell this information to pharmaceutical companies, which can churn out personalized cures. Otherwise, they could let it into other hands. So, our genetic heritage contains information, a gold mine for business. If suddenly, on your PC, you receive an advert for a cream, or a wine dedicated only and exclusively to you, you should be aware that this is the outcome of a powerful profiling campaign.

GIORGIO MOTTOLA

What do they do with our genetic data?

HELEN WALLACE - BIOLOGIST - DIRECTOR GENEWATCH

They can use it primarily for marketing, what I call genetic marketing, based on what the DNA test reveals out us.

GIORGIO MOTTOLA

So genetics can be applied to marketing?

ANDREA CRISANTI - PROFESSOR OF MOLECULAR BIOLOGY, IMPERIAL COLLEGE

It sure can! It can be applied to marketing to prompt associations between smell and taste sensations with certain products.

SERGIO PISTOI - BIOLOGIST AND WRITER

If you want, let's do a little experiment.

GIORGIO MOTTOLA

Sure... .

SERGIO PISTOI - BIOLOGIST AND WRITER

Take one of these ...

GIORGIO MOTTOLA

Here we go.

SERGIO PISTOI - BIOLOGIST AND WRITER

I'll take one too ... now you taste it, like a sweet. Does it taste bitter?

GIORGIO MOTTOLA

No.

SERGIO PISTOI - BIOLOGIST AND WRITER

What do you taste?

GIORGIO MOTTOLA

I taste nothing.

SERGIO PISTOI - BIOLOGIST AND WRITER

Nothing? But I find it has a very strong bitter taste. This means that there are people who perceive ... they are called tasters, like me ... who perceive the bitter taste of this substance, which is contained in many bitter foods, for example cabbage, Brussels sprouts, and what's the idea: that in reality two different people, sitting at the same table perhaps in a fine restaurant, well like it or not, they will perceive tastes in a very different way without even realizing it.

GIORGIO MOTTOLA

And so we will also have genetic cuisine at some point!

SERGIO PISTOI - BIOLOGIST AND WRITER

Who knows, who knows!

GIORGIO MOTTOLA OFF-SCREEN

It sounds like science fiction but genetic marketing has been around for almost 10 years. In 2008, Ingenuity System, a Silicon valley company specializing in

biotechnology, patented genome-based advertising, which allows adverts to be directed in relation to the user's biological characteristics.

SERGIO PISTOI - BIOLOGIST AND WRITER

If my genetic profile indicates that I am perhaps likely to have high cholesterol, then instead of advertising snacks, I will receive adverts about foods with less fat because I will be more responsive.

GIORGIO MOTTOLA OFF-SCREEN

And if there are genetically customized advertisements, this means there are also genetically customized products. The new frontier of genetic marketing has already been crossed here, not far from Lake Garda, where a couple of years of some young entrepreneurs started producing customized creams based on DNA.

FRANCESCO RIZZOTTI – CHEMICAL ENGINEER - HEKATÈ COSMETICS

We use your DNA to build personalized cosmetics from scratch. For example, skin structure: if we understand that a certain gene does not synthesize enough collagen, we include this ingredient in the cosmetic product at a concentration in proportion to the genetic level.

GIORGIO MOTTOLA

And does it really work?

FRANCESCO RIZZOTTI – CHEMICAL ENGINEER - HEKATÈ COSMETICS

Self-assessment tests performed by our customers indicated that they noticed the difference.

SERGIO ABRIGNANI - DIRECTOR, NATIONAL MOLECULAR GENETICS INSTITUTE

We have no basis today for saying that perfumes or creams can have different effects based on our genetics. Someone may perhaps find out that it's true but today ...

GIORGIO MOTTOLA

Yet some of these products are sold in pharmacies today.

SERGIO ABRIGNANI - DIRECTOR, NATIONAL MOLECULAR GENETICS INSTITUTE

Pharmacies sell just about everything.

GIORGIO MOTTOLA

So, we do not know if it works scientifically.

FRANCESCO RIZZOTTI – CHEMICAL ENGINEER - HEKATÈ COSMETICS

So ... not scientifically but objectively, ok? I say this out of intellectual honesty.

GIORGIO MOTTOLA OFF-SCREEN

And if you do not need a beauty cream but a soul mate, there is someone in a town near Zurich who is willing to find you even through DNA.

JOËLLE APTER - GENETIST, GENEPARTNER

Love is not a coincidence. When we meet someone, we immediately understand whether we like them or not. Our instincts, our body, tell us this. So, we at GenePartner do this without the need to meet, so that people understand beforehand

if they will really be attracted to each other. By matching their DNA, we find out if they are biologically compatible and if they will be a long-term couple.

GIORGIO MOTTOLA

What are the advantages of being with another person with whom you are biologically compatible?

JOËLLE APTER - GENETIST, GENEPARTNER

Sex life is much more satisfying and there is a greater chance of becoming pregnant and having healthy children.

GIORGIO MOTTOLA OFF-SCREEN

Like many other DNA-based dating sites, the method is founded on scientific tests conducted by a Swiss geneticist which would show how each of us would be systematically attracted to people with whom there is genetic "harmony".

JOËLLE APTER - GENETIST, GENEPARTNER

By matching DNA, we can also say what level of attraction exists between two people: here, for example, it is very high at 78%. This is another interesting aspect. The test also says what kind of attraction exists: DNA can help understand whether like the other person you only as a friend or if you want to meet for a date.

GIORGIO MOTTOLA

So if you want to leave someone, you can now have scientific proof!

JOËLLE APTER - GENETIST, GENEPARTNER

Exactly, you have scientific proof for saying: "let's just remain friends".

SERGIO PISTOI - BIOLOGIST AND WRITER

Any biologist, in my opinion, can say, can confirm that these are a rather wobbly scientific bases.

GIORGIO MOTTOLA OFF-SCREEN

But not only small start-ups have plunged into personalized products. Illumina, one of the giants in genetics worth over 30 billion dollars on the market, recently launched the Helix company, where can supply a wine suitable for your DNA for the modest sum of \$109 or buy a scarf made to measure for the your genetic code for only \$229.

GIUSEPPE TESTA - MOLECULAR BIOLOGIST AND BIO-ETHICIST, IEO UNIVERSITY OF MILAN

The possibility that the test reading a snippet of your DNA is then predictive, i.e. can tell, from that bit of DNA, whether or not you will like that wine, etc., is naturally still to be proven. Let's say it's an interesting example of very aggressive marketing ...

SIGFRIDO RANUCCI IN THE STUDIO

A word of warning for web surfers: keep an eye out for bluffs. Because there is the risk once research into our genetic heritage leaves the laboratory. On the other hand, if you take these tests in public health facilities, then you can predict predisposition to some diseases. For example, it is possible to predict ALS, cystic fibrosis and muscular dystrophy, as well as Alzheimer's or Parkinson's. Diseases, unfortunately, for which there is no cure; while tests can save lives in cases of thyroid, colon, breast and ovary cancers. This was the case, for example, for Angelina Jolie who, after having

sequenced her DNA, decided to remove her breasts and ovaries to avoid the onset of certain problems. In this context, Report has already decided to publish on its website information about how and when to take the test and the centres to turn to even for prevention. After the advertising break, we will take a look at the largest genetic bank in the world. Google is setting it up with massive secrecy.

Web giants are investing in our genetic heritage. Google is already in possession of the medical records of one and a half million patients and is secretly setting up the largest genetic bank in the world. It has already sold genetic test data, including those involving our Giorgio Mottola, to the pharmaceutical industry. Because it is there, in this sector, that the revolution is unfolding.

GIORGIO MOTTOLA OFF-SCREEN

However, don't assume that everything is limited to personalized advertising banners and genetic junk: the true gold mine for the genetic revolution is the pharmaceutical industry.

RICCARDO SABATINI - SCIENTIST AND ENTREPRENEUR

At a very basic level, a drug is a molecule that must travel around your body and activate or deactivate a function, one of these operators, one of these proteins. This molecule is designed for the overwhelming majority: some people absorb more of it, some less, and some people do not absorb certain drugs.

GIORGIO MOTTOLA OFF-SCREEN

It is a problem that may be solved thanks to DNA research: the way we treat ourselves will change completely through personalized medicine, no longer a single cure for a specific disease but different treatment for each individual patient.

RICCARDO SABATINI - SCIENTIST AND ENTREPRENEUR

In ten, maybe 15 years' time, instead of choosing a drug that may already be on the market, I will be able to design one just for you. I take the shape of your specific protein, I build and I adapt a drug that I know already works more or less well, I personalize it and that is the next step.

GIORGIO MOTTOLA

So one day we will practically have personalized aspirin.

RICCARDO SABATINI - SCIENTIST AND ENTREPRENEUR

Yes, everything is needed in the ecosystem, hospitals, doctors, etc. will have to be updated and this is a new stage.

GIORGIO MOTTOLA OFF-SCREEN

As early as 2005, leading financial consulting firm Price Waterhouse Coopers suggested that industries in this sector should invest in customised drugs. Today it is no longer just advice. For many pharmaceutical companies, it could be a matter of life or death. The patents on some of the most profitable drugs will expire within the next 5 years and no more patent means the end of exclusive sales. According to a global data report, Big Pharma risks a loss of about 65 billion euros by 2019.

GIORGIO MOTTOLA

Will genetic drugs be the business of the future for pharmaceutical companies who must try to recover losses caused by the expiry of patents?

SERGIO DOMPÉ - PRESIDENT, DOMPÉ FARMACEUTICI

Yes, you are absolutely right. However, so-called "precision medicine" involves analysis, involves developments that are incredibly expensive.

STEFANO GUSTINCICH - DIRECTOR OF LIFE SCIENCE-ITALIAN INSTITUTE OF TECHNOLOGY

You must always bear in mind that the cost for a molecule from the laboratory through to the pharmacy on average is 2 billion euros.

GIORGIO MOTTOLA OFF-SCREEN

In just a few years, mass drugs may well be replaced by personalized variants but the most worrying consequence could be that of costs.

SERGIO DOMPÉ - PRESIDENT, DOMPÉ FARMACEUTICI

This would significantly increase development times and costs and considerably reduce the number of potential users. So, costs will skyrocket.

STEFANO GUSTINCICH - DIRECTOR OF LIFE SCIENCE-ITALIAN INSTITUTE OF TECHNOLOGY

The problem is becoming a political problem, that is, it has become a problem of agreement between pharmaceutical companies, States and health systems, because it is clear that a health system cannot afford a drug for a chronic disease that costs 50,000 euros per bottle.

GIORGIO MOTTOLA OFF-SCREEN

If a great deal of care is not taken, we risk undermining a health system such as that in Italy and elsewhere which, by constitution, must ensure all necessary care for all citizens.

There are already 316 different types of genetically customized drugs currently on the market; more than 80% concern oncological diseases. Cancer is the main field where genetic research and personalized medicine are beginning to make the difference.

RICCARDO SABATINI - SCIENTIST AND ENTREPRENEUR

We are building the instruction manual for reprogramming and, even better, reactivating your immune system. We not long attack cancer, we teach and reactivate your immune system.

Exceptional, if we do it!

STEFANO GUSTINCICH - DIRECTOR OF LIFE SCIENCE-ITALIAN INSTITUTE OF TECHNOLOGY

This is a particularly exciting moment from this point of view. While exaggerating, we can say that every patient has a different cancer because it has a combination of particular mutations; this means we should find a specific drug for each mutation.

GIORGIO MOTTOLA OFF-SCREEN

The main company in the world conducting genetic research in the oncology field is Grail, funded web billionaires Bill Gates and Jeff Bezos. Right behind comes Calico, the scientific arm of Google. Over the past year, they have each invested over \$1 billion.

STEFANO GUSTINCICH - DIRECTOR OF LIFE SCIENCE-ITALIAN INSTITUTE OF TECHNOLOGY

Since the genomic technologies that can be applied, big data analysis, to cancer diseases can also be applied to other extremely varied diseases, huge investments are being made in all fields of medicine and in diseases.

GIORGIO MOTTOLA OFF-SCREEN

Amazon, Microsoft, Facebook and Google for some years now have set foot in the world of medicine and health: Amazon has started a secret project called 1492 that tests genetic drugs in the field; In recent years, Microsoft has invested in 45 health companies ranging from patient monitoring in hospitals, to fitness apps and 3d physical and cognitive rehabilitation. Facebook, on the other hand, initially launched the facebook health department and then the Zuckerberg Chan Initiative.

PRISCILLA CHAN - ZUCKERBERG CHAN INITIATIVES

Our goal is to conquer and manage all diseases by next century.

ZUCKERBERG CHAN INITIATIVES

There are many brilliant scientists but few capable of building tools for the entire scientific community.

GIORGIO MOTTOLA OFF-SCREEN

In this video, the Zuckerbergs announced an investment of \$45 billion over the next 10 years, presenting it as a charity initiative.

GIANMARCO BARDELLI - FINANCIAL ANALYST

Not really charity - since the vehicle chosen is an LLC, which is very similar to an Italian srl (limited company).

GIORGIO MOTTOLA

And what does this mean?

GIANMARCO BARDELLI - FINANCIAL ANALYST

All the profits generated by investment activities may be reinvested in new activities without giving rise to conflict with tax legislation.

GIORGIO MOTTOLA

Listen, but is the aim really to avoid paying tax on 45 billion euros?

GIANMARCO BARDELLI - FINANCIAL ANALYST

It's sure that the taxes will not be paid now ...

GIORGIO MOTTOLA OFF-SCREEN

Yet among internet giants, the one investing the most is Google.

GIUSEPPE TESTA - MOLECULAR BIOLOGIST AND BIO-ETHICIST, IEO UNIVERSITY OF MILAN

Well, Google's long-term project is to become a major, if not actually the main player in new medicine.

GIORGIO MOTTOLA OFF-SCREEN

Its interest in medicine and genetics emerged in 2005 when, at the annual billionaires dinner, Google's two founders - Sergey Brin and Larry Page - met Craig Venter, the man who in 2000 helped to map the genome.

GIUSEPPE TESTA - MOLECULAR BIOLOGIST AND BIO-ETHICIST, IEO UNIVERSITY OF MILAN

They met at dinner and, shall we say, talked about how to put together Google's amazing skills with the possibility of launching "do it yourself" genetics. And this, how shall we put it, interesting yet problematic concept came about: create in this way millions of mini scientists, that is, people who log on with computers, who presumably have direct access to their own DNA and Google virtually acts as an intermediary since, depending on what it reads from your DNA, it tells you immediately what you want to know about potential predispositions to the disease and perhaps even where you can go for treatment and so on.

GIORGIO MOTTOLA OFF-SCREEN

Shortly after that dinner, 23andMe was founded and began building a full-scale empire in the genetics, health and biotechnology field. Google created two companies dealing exclusively with scientific research - Calico and Verily - and invests in 78 companies involved in every aspect of health from apps to monitor diseases, contact lenses that measure blood sugar, spoons for Parkinson's patients and storage of genetic data.

HELEN WALLACE - BIOLOGIST - DIRECTOR GENEWATCH

These huge companies want access to our health data. Google would like to have the monopoly of all our genetic information.

GIORGIO MOTTOLA OFF-SCREEN

To understand how all this could completely change the way we treat ourselves through such internet giants, we have to go to Boston which is currently the world capital of the DNA revolution.

RODRIGO MARTINEZ - MARKETING DIRECTOR, VERITAS GENETICS

This is Alexa, the virtual assistant created by Amazon. We connected Alexa to a human genome. Would you like to see how it works?

GIORGIO MOTTOLA

Yes, please.

RODRIGO MARTINEZ - MARKETING DIRECTOR, VERITAS GENETICS

Alexa, how's my cholesterol doing?

ALEXA - FEMALE ROBOT VOICE

I would like to remind you that you have a genetic predisposition for high cholesterol. Would you like me to book a restaurant that makes low-calorie food?

RODRIGO MARTINEZ - MARKETING DIRECTOR, VERITAS GENETICS

No thank you, Alexa.

GIORGIO MOTTOLA

So can you ask Alexa anything about your health?

RODRIGO MARTINEZ - MARKETING DIRECTOR, VERITAS GENETICS

Alexa helps you use your genetic information to make decisions about every aspect of your life. Be it going to a restaurant, the supermarket or the pharmacy ...

GIORGIO MOTTOLA OFF-SCREEN

Veritas is one of dozens of companies in Boston that, starting from genetic research, is developing a system that will replace, at least in part, doctors and hospitals with a simple mobile app.

RODRIGO MARTINEZ - MARKETING DIRECTOR, VERITAS GENETICS

We have to get DNA out of labs and take it to the consumer world. We must no longer think of people as patients but as consumers.

GIORGIO MOTTOLA

And what does that mean?

RODRIGO MARTINEZ - MARKETING DIRECTOR, VERITAS GENETICS

Since DNA came out of the laboratories, the boundaries between diet, health, drugs and doctors have become blurred. Beforehand, only a doctor had the information needed to decide how to treat you.

GIORGIO MOTTOLA OFF-SCREEN

But if the new DNA economy is to take off, it desperately needs data.

SERGIO PISTOI - BIOLOGIST AND WRITER

If I have to understand the genetic basis causing a predisposition to diabetes or heart attacks, what I obviously have to do is take the DNA of thousands of healthy people and thousands of sick people, compare them with each other and then see statistically if there it's a difference, maybe a gene, a variation in a gene that can explain this predisposition.

GIORGIO MOTTOLA

DNA can only be studied through huge numbers.

SERGIO PISTOI - BIOLOGIST AND WRITER

That's so, today.

FEMALE VOICE, BASELINE PROJECT

What if you could impact the lives of millions of people simply by sharing your health data?

GIORGIO MOTTOLA OFF-SCREEN

This is why Google started an initiative such as the Baseline project.

FEMALE VOICE, BASELINE PROJECT

We started by monitoring 10,000 people who share our purpose.

STEFANO GUSTINCICH - DIRECTOR OF LIFE SCIENCE-ITALIAN INSTITUTE OF TECHNOLOGY

This project, starting with 10 thousand individuals, collects and sequences the genome and at the same time collects a whole series of physiological parameters 24 hours a day during the life of a person. Pressure, temperature, the presence of certain molecules in the blood and so forth, thereby creating a huge database.

GIORGIO MOTTOLA

How much do we know about the scientific research undertaken by Google?

ANDREA CRISANTI - PROFESSOR OF MOLECULAR BIOLOGY, IMPERIAL COLLEGE

Not very much at all, unfortunately, because Google has implemented a strict secrecy policy so that every time a researcher is practically employed by Google, such as one of our colleagues, he or she practically disappears into a kind of black hole.

GIORGIO MOTTOLA OFF-SCREEN

But the most highly desired data is held by hospitals and Google, through one of its companies - Google Deepmind - has managed to access this information in England.

HELEN WALLACE - BIOLOGIST - DIRECTOR GENEWATCH

Google Deepmind has taken the medical records of patients in the British public health system.

GIORGIO MOTTOLA

Why did they give Google all this information?

HELEN WALLACE - BIOLOGIST - DIRECTOR GENEWATCH

The aim was to develop an app to predict some types of disease. The problem is that they have broken many privacy laws concerning the privacy of patient data. The hospital gave Google information that had nothing to do with the project and above all without asking patients for information.

GIORGIO MOTTOLA OFF-SCREEN

According to the Privacy Guarantor in Britain, this hospital released the medical records of one and a half million English patients that ended up directly in Google's databases.

GIORGIO MOTTOLA

And how valuable is all this data?

HELEN WALLACE - BIOLOGIST - DIRECTOR GENEWATCH

Extremely valuable. From a business point of view, this information is worth a great deal of money precisely because it information cannot be found so easily with research projects.

GIORGIO MOTTOLA OFF-SCREEN

Even in Italy, albeit in a completely legal way, hospitals could soon begin to share their health data with a technological giant. IBM has in fact launched a project to use its artificial intelligence systems the in public health sector.

ROBERT ALEXANDER - IBM HEALTH AND LIFE SCIENCES MEDICAL ARCHITECT

Artificial intelligence can accelerate the response of a geneticist by helping to find in scientific literature written in human language correspondences with the problems of the person in question and therefore significantly speed up the possibility of providing an answer that makes the patient feel better.

GIORGIO MOTTOLA

So IBM's artificial intelligence accelerates diagnosis ...

ROBERT ALEXANDER - IBM HEALTH AND LIFE SCIENCES MEDICAL ARCHITECT

It accelerates the items needed by the geneticist or doctor to arrive at a diagnosis, yes.

GIORGIO MOTTOLA OFF-SCREEN

Yet for it to work, the IBM system has to gather data from the medical records of millions of patients. And this gives rise to concerns over privacy.

GIORGIO MOTTOLA

Once you have used this data to make the system work, what do you do? Do you resell them?

ROBERT ALEXANDER - IBM HEALTH AND LIFE SCIENCES MEDICAL ARCHITECT

The data is not ours. We develop the data, after it disappears, is deleted. We do not process them in any other way.

GIORGIO MOTTOLA

In other words, you do not share this information with third parties?

ROBERT ALEXANDER - IBM HEALTH AND LIFE SCIENCES MEDICAL ARCHITECT

Absolutely not. Never.

GIORGIO MOTTOLA OFF-SCREEN

The agreement between IBM and the Italian government was signed last year by Prime Minister Matteo Renzi. On that occasion, IBM announced an investment in Italy totalling more than 150 million euros and the project to use data from the National Health System soon emerged.

GIORGIO MOTTOLA

Given the timing, one would be forgiven for thinking this is no mere coincidence. That is, IBM began to invest in Italy and in return the government guaranteed access to Italian health data.

ROBERT ALEXANDER - IBM HEALTH AND LIFE SCIENCES MEDICAL ARCHITECT

You have a perverse mind. I do not see this association.

GIORGIO MOTTOLA

Ok

SIGFRIDO RANUCCI IN THE STUDIO

Perhaps we are a little perverse. But if this is the road forward, sooner or later we will find Google, Amazon, Apple or Facebook acting as our family doctor. The direction is to treat ourselves using apps. Yet the privacy guarantor said: "Apps that deal with health have shown worrying gaps as regards the protection of personal data". What is at stake here is our genetic heritage. Will national states, which have always been prone to the excessive power of web multinationals, be able to control them over such a sensitive issue as health? Google has certainly not signed the Hippocratic oath; and in the absence of public control, the risk is that individual freedoms and protections will be lost. Remember this number (1313) .. and it certainly isn't a lucky one.

GIORGIO MOTTOLA OFF-SCREEN

In Britain, to avoid mass genetic data being studied and used only by multinationals and private entities, the Ministry of Health has launched England Genomics, a entirely public project that aims to build a database with the DNA of one hundred thousand English people.

RICHARD SCOTT - CLINICAL LEAD GENOMICS ENGLAND

We started England Genomics because we understood that using genetics in healthcare was a great opportunity. And we wanted all British citizens to benefit from it.

GIORGIO MOTTOLA OFF-SCREEN

All patients in the British healthcare system can take part in the project, like Arthur.

ARTHUR

My name is Arthur, my mother is Zena and my sister is Annais.

ARTHUR'S MOTHER

We realised that Arthur had eye problems when he still was very young. Doctors diagnosed him with albinism. Which means that Arthur could be almost blind for the rest of his life. And the cause is genetic. This is why we joined England Genomics to find out more about his illness and give Arthur the hope of a better life. We know that all his data will be in a file forever but it is the only way to help scientists study the disease and do something for all children who have the same problem as Arthur.

GIORGIO MOTTOLA

Why is it so important to involve such huge amounts of DNA data?

RICHARD SCOTT - CLINICAL LEAD GENOMICS ENGLAND

Some diseases sometimes depend on just one letter in the DNA sequence. So, discovering the origin of the disease means we have compare the DNA of sufferers with that of thousands of other patients. It is only in this way that we can gain a better understanding exactly where in the DNA the problem lies and then seek a solution. This is why we need to compare at least 100,000 DNA samples.

GIORGIO MOTTOLA

How do you protect the privacy of patients who give you their data?

RICHARD SCOTT - CLINICAL LEAD GENOMICS ENGLAND

First of all, we only recruit people who say they want to participate in the project and only if they are fully aware of what it means to donate their DNA.

GIORGIO MOTTOLA OFF-SCREEN

All this attention to privacy is more than justified. If, as we have seen, DNA can be an unprecedented opportunity, there are also incalculable risks if genetic information is not handled in the right way.

ANTONELLO SORO - PRESIDENT OF THE PRIVACY AUTHORITY

The risk is that whoever holds this information can use it to restrict your freedom.

GIORGIO MOTTOLA

In what way?

ANTONELLO SORO - PRESIDENT OF THE PRIVACY AUTHORITY

If an insurance company finds out that you have a high probability of having a certain illness, it would certainly offer an insurance policy on different terms than are generally offered. If an employer finds out that you are probably subject to a certain illness, it is likely that they would think about it while considering to take you on or not.

GIORGIO MOTTOLA OFF-SCREEN

And that's exactly what could happen in a few months in the United States where the American Congress is about to approve Law 1313 that reforms the operation of the so-called welfare programs managed by insurance companies.

LISA SHAGLER - VICE-PRESIDENT, FORCE

Here in the United States, companies pay the health costs of their employees. That's why they want their workers always to be healthy. It means that health insurance is cheaper. And this is precisely what wellness programs are for: they ensure that workers keep healthy.

GIORGIO MOTTOLA

So, workers are practically obliged to be healthy?

LISA SHAGLER - VICE-PRESIDENT, FORCE

If not healthy, at least in their best form. In fact, insurance companies can ask you to take exams: for cholesterol, diabetes, blood pressure. And if these exams find something wrong, you have to take part in health programs, managed by the insurance companies themselves. Today it is optional, but with Law 1313, you could be forced to do all the exams asked of you.

GIORGIO MOTTOLA OFF-SCREEN

And the exams required by the insurance companies, thanks to the new law, will also include a DNA test to establish which diseases the worker may be genetically predisposed to.

LISA SHAGLER - VICE-PRESIDENT, FORCE

If they refuse to take the test, they could pay a fine of tens of thousands of dollars.

NANCY COX - PRESIDENT, AMERICAN SOCIETY OF HUMAN GENETICS

If an employer finds out that one of his employees has a genetic predisposition to a very expensive disease to treat, he can sack him or her. The worker could sue the company but genetic discrimination is very difficult to prove in court.

GIORGIO MOTTOLA OFF-SCREEN

The law was presented to Congress after Trump's election and is supported by the entire Republican Party.

MR BYRNE - REPUBLICAN DEPUTY

Thanks to this law, we should be able to reduce the costs of health coverage. I see no violation of American laws concerning genetic discrimination.

GIORGIO MOTTOLA OFF-SCREEN

A few years ago, the United States introduced safeguards for people with genetic predisposition to certain diseases. These safeguards, if the new law is approved, may in some cases be eliminated.

GIORGIO MOTTOLA

Have there been any cases of genetic discrimination in the US recently?

LISA SHAGLER - VICE-PRESIDENT, FORCE

The last occurred a few months in Rhode Island: a woman sued Tiffany, the company where she'd worked for years. When she discovered that she had a genetic predisposition to breast cancer that required surgery, Tiffany told her that her job no longer existed and that they could only offer her another much lower paid job.

GIORGIO MOTTOLA OFF-SCREEN

European laws are much more restrictive than in the US but will we run the same risks in Italy in the future?

ETTORE CAPOLUONGO - DIRECTOR, IDI MOLECULAR BIOLOGY CLINIC

The risk, if there is no reference standard that seeks to protect the integrity of individuals, is certainly possible.

GIORGIO MOTTOLA

But should I pay more simply because I have a greater predisposition to a given illness?

SERGIO ABRIGNANI - PRESIDENT, NATIONAL MOLECULAR GENETIC INSTITUTE

When you sign up for car insurance, they ask you how many accidents you had the year before and you pay more if you did have an accident. In some cities of Italy, insurance is much more expensive because there are many more thefts and they know this because they have databases.

ANTONELLO SORO - PRESIDENT OF THE PRIVACY AUTHORITY

DNA is quite another thing compared to geographical origin or the number of accidents.

GIORGIO MOTTOLA

So you would rule out that DNA will be included among insurance risk factors in Italy.

ANTONELLO SORO - PRESIDENT OF THE PRIVACY AUTHORITY

I hope so.

SIGFRIDO RANUCCI IN THE STUDIO

We certainly hope so, too. In America, where such trends emerge earlier, Law 13-13 is currently under discussion. The mere idea that the possibility of an illness discovered through a mandatory DNA test may be an opportunity to propose more expensive health insurance or an underpaid job makes you shiver. Laws currently protect us; however, the genetic census has already started and web multinationals are also on the move. Yet before the horse has bolted out of the stables, privacy authorities must be given more tools. All this is not without a certain regret. In 1987,

the Italians were the first to have an inkling through Nobel Prize Winner, Renato Dulbecco. He had launched the project to map the entire human genome. Yet in 1995, the President of the National Research Council called him and said: "I'm sorry, we've run out of money, you'll have to go home". Today we are chase again and also talking. We are obliged to. Talk about "vision".