Gene-Chain, Version 1.0

Inception:

EncrypGen was created to fulfill the goals and interests of founders - Dr. David Koepsell, an attorney, ethicist, and author who has penned numerous books and articles on genes, ownership and ethics, and his wife Dr. Vanessa Gonzalez Covarrubias, a pharmacogenomic research scientist. EncrypGen embarked on a mission to create a platform that would increase the amount of genetic data available for research, while simultaneously increasing privacy, security, and ownership of data for individuals and allow them profit from their data in an open marketplace.

The model for genetic data sharing and marketing for science has been dominated by large direct-to-consumer DNA testing companies for a decade. Most of the bulk genomic data sales to date have been done by companies like 23andMe from their inventory of over 5 million sets of data from paying customers. Most of these users have agreed (often, it seems, without realizing what they were consenting to) to let their data be used (sold) for science. With multiple bulk data deals in the tens to hundreds of millions of dollars, the DNA testing companies are profiting from their customer's data, yet the customers whose data is being sold do not receive any compensation or any notice of where their most sensitive data is being sent, or how it's being stored.

EncrypGen's mission is to give individual consumers control over the use of their data and to reward them for their contributions to science and medicine. The Gene-Chain, EncrypGen's proprietary blockchain, leverages the benefits of emerging blockchain technologies to help to achieve those goals. Blockchains, such as the original and best known Bitcoin, are distributed, cryptographically-secured, immutable ledgers. The benefits of blockchains include: security of transactions, auditable and public record keeping, extremely difficult to hack or otherwise manipulate, and they help to alleviate problems of lack of trust among parties of transactions.
There are legal and regulatory issues that must be considered when building a solution for sensitive data using blockchains, as discussed in a bit more detail below, but blockchains provide a unique and sought-after means of addressing concerns of privacy, security, and transparency in numerous types of transactional applications.

EncrypGen was founded to begin the task of creating the world’s first blockchain-mediated market for genomic data. Since its inception, EncrypGen has met every milestone on their roadmap on or ahead of schedule.

- In May of 2017, the team demoed a prototype at the Bio-World IT conference in Boston.
- During the Festival of Genomics in London in January of 2018 the beta of the platform was unveiled.
- Finally on November 6 of 2018, the company publicly launched Gene-Chain Version 1.0 and conducted the first free market genomic data sale on the blockchain using the newly created DNA cryptocurrency.

Requirements:

The Gene-Chain was intended to solve problems affecting science and society, and to give power and share wealth with those who choose to offer their genetic data for the sake of scientific advancement. Because the next wave of scientific and medical advances in genetics will depend upon an ever increasing amount of data, rapid and easy access to new data must be facilitated for studies and labs of all sizes, not just the Pharma giants that can afford multi-million dollar deals from the big DNA testing companies.
The very nature of scientific advancement requires that researchers of all types have access to enough data and the research of others in order for them to be able to advance their own research, but today, the monopoly of a few keeps data from the general research community and in the hands of proprietary commercial operations.

In a genomic data marketplace, user identities must be carefully protected as genomic data has the risk of revealing things about individuals that they wish to keep private. It must also allow researchers to search for datasets of value to their research. This means parsing raw genomic data for fields that researchers need to search upon, such as common tags for variants in individual genomes, as well as correlating that raw genetic data with self-reported data about the owners of the data, like medical, demographic, lifestyle and other behavioral information. It is the combination of these data points that allows researchers to search for correlations that can be medically and scientifically valuable. Finally, the solution must include a mechanism for payment and leave an immutable audit trail for transactions. The Gene-Chain accomplishes all of these.

Because in the summer of 2018 new laws (GDPR) went into effect in Europe intended to protect individual data privacy, a number of new requirements were added to the task list devised for the Gene-Chain Development Team. Importantly, and complicating the role of the blockchain in the product, the new EU rules require anyone to be able to delete their personal data from any provider’s platform. This means that the role of the blockchain for any genomic blockchain product must necessarily be limited, pending new breakthroughs in typical blockchain technologies. Because blockchains permanently preserve data, the new EU requirements cannot be satisfied if genomic data is put on a blockchain. This is because, as has been revealed by a number of studies, genomic data alone may be re-identifiable when combined with public data.
Blockchain:

The Gene-Chain is powered by a custom-built blockchain, whose code is built on Multi-Chain, and which is capable of a lot more than it will be doing initially in our product. We will reveal more about that in the near future, but suffice it to say we have interest already for spin off projects and products that can serve as additional income streams for the company.

The Gene-Chain, the blockchain that Dr. Notis Gasparis built, is the heart of the marketplace we launched in November 2018. It captures and processes all the transactions that will comprise the free market of genomic data we have made. It is a record of those transactions, and is ultimately agnostic about the assets used to buy and sell the data, being able to take in now Bitcoin (BTC), and later Ethereum (ETH) and any other crypto assets, as well as fiat assets, and then fulfill transactions using mDNA, the Multi-chain DNA cryptocurrency on the platform. mDNA improves liquidity as it allows token holders to cash out in BTC for now, and then later as we adopt the ETH and ERC20 DNA (eDNA), it will provide people with a way to use their eDNA tokens (DNA), rewarding them 1:1 for each mDNA token they earn or hold.

The brains of the Gene-Chain were built by our developers for the DNA data portions of the platform, and this platform is no less remarkable. Using HIPAA compliant, and highly secure cryptographically-protected data storage and Google Cloud, the platform allows for all the functionality necessary to launch a valuable genomic marketplace. That is to say, it is driving the profile creation, the anonymity of users, many layers of abstraction between users and their data for identity protection and privacy, processing of genomic data files of various types by way of indexing, which brings usefulness to the researchers who will search for and buy data, and finally data delivery in a proprietary CSV file stripped of identifying information. Eventually, we will create a browser for viewing purchased files so that greater control over data is maintained by sellers, and all of the flexibility we now will depend on for the next iterations of this amazing product are due to the craftsmen like Notis and his team and their work with our blockchain, working together to forge a complete product.
That product allows people now, if they have BTC, to search for and buy user-submitted genetic data using our platform token, mDNA. Starting in November 2018, that market, for the very first time, allows anyone to buy genomic data and for users to be directly paid for that data. Anyone with files from 23andMe, Ancestry, and Codigo46 may already start selling their data. Indexing capabilities with other brands of DNA test kits will be added on an ongoing basis. The enormity of this accomplishment cannot be overstated. No other entity or project in the genomic data space is close to this accomplishment, giving EncrypGen first mover advantage and a significant lead in terms of product developments and the flow of data over all competitors in the space.

The market space for genomic data is enormous, even with numerous competitors. As with any nascent industry it’s important to develop standards and practices that will help advance the industry ethically and sustainably, which is why EncrypGen launched the Genomic Blockchain Consortium last year. In addition to his role as CEO and board member of EncrypGen, Dr. Koepsell is chairing the Genomic Blockchain subcommittee of the Blockchain in Healthcare Global—IEEE-ISTO initiative of which he is a founding board member. The goal of each initiative is to help facilitate standards and interoperability among healthcare related blockchain companies and to thus protect customers, their data, and its security.

The Market for Genomic Data:

![Projected Genomic Data Markets](image)

The genomic data market is both extremely valuable and highly competitive. Genomic data is certainly going to be highly valued and immensely profitable, and there is room for any number of competitors to begin to use Blockchain technologies to help individuals profit from their data,
and increase its availability for science. To date, the main model for genomic data use in bulk for research has grown around the services and contracts provided by direct-to-consumer genetic testing companies. Those companies have made enormous inroads into the consumer market while selling their testing services at deep discounts representing millions of USD worth of losses. Those losses have been predicated upon the notion that they would be recouped, and indeed huge profits realized on the sales of data that their customers agree to have resold. 23andMe has yet to turn a profit, and until recently the viability of their model may have been doubtful.

In the summer of 2018, however, 23andMe received an investment of nearly 300 Million USD from pharmaceutical giant GlaxoSmithKlein involving a 4 year exclusive access guarantee. This brought the total investment into 23andMe to nearly 1 billion USD, even while the company has yet to realize a profit. Since then, their customer base continued to grow, and they have slashed prices for their tests in time for the Christmas season, which last year proved to be a very popular gift item as they moved close to a million units. One of the glaring problems with the GSK deal is that it blocks every other lab and study from accessing the largest repository of DNA data. That's not good for science, medicine or humankind.

Whether they have done so knowingly or not, to date nearly 80% of 23andMe customers have agreed to have their data sold for science. It was recently calculated that had everyone whose data was used by (sold to) 23andMe’s data buyers been paid directly, they would have received about 130 USD each. With each data set being used in an average of 200 studies, it’s easy to see there is tremendous potential for consumer who have their DNA tested, to profit from sharing their test results and other phenotypic data...repeatedly. The value of those data sales one might expect now as a 23andMe customer may have doubled with the GSK deal. In sum: the market for buying and selling data is enormous.

What brings significant value to the datasets currently being curated and sold by companies like 23andMe is the addition of user-created health profile data, allowing researchers to do searches on correlations between that data and the raw genetic data provided from a DNA test. The Gene-Chain disintermediates this process, allowing customers to take their raw DNA data file, complete a profile, and interact directly with data buyers interested in buying the data directly from consumers of genetic testing, and to receive payment themselves with just a small commission being kept by EncrypGen, and shared with the developers and maintainers of the Gene-Chain marketplace.

A free market for genetic data is especially necessary if GSK and other companies begin to monopolize the buy side as 23andMe monopolize the sell side. These sorts of monopolies threaten not only the broad and democratic availability of crucial data for basic science, but also the prices of that data, effectively pricing small companies and research labs out of the space
and potentially inhibiting new discoveries. Blockchain are well suited and imbued with the values behind transparency, democratization, individual ownership, and cooperation. EncrypGen’s Gene-Chain is intended to be the model for a solution consistent with these values. It launched November 6, 2018 and users are responding, uploading their data and attracting buyers to engage with the platform. The very first disintermediated sales of genomic data from individuals to researchers have already begun to occur on the Gene-Chain.

The Competition:

LunaDNA

LunaDNA has given up on a cryptocurrency which distances them a bit from being a direct competitor. They have opted for giving donors of data to their database shares in a public benefit corporation. This is a safe regulatory move given the uncertain climate around cryptocurrency in the US, but one has to question whether ordinary customers will care about shares. They are simply not very fungible for regular people. Would most people opt for shares in a startup over a currency you can spend right now? It seems doubtful. Moreover, LunaDNA has not announced even an alpha version, nor are they likely to this year. Without blockchain or crypto in their business plan, interest in their platform is likely to fade away, and without a fungible means of compensating data donors, filling a database with data is going to be a challenge. Another problem with shares is that shareholders have absolutely no anonymity. So this must dilute LunaDNA’s palatability for users concerned with their privacy.

Nebula Genomics

Nebula is a fine concept, with serious people involved. Notably, George Church, whose sequencing company Veritas is the major benefactor and stands most to profit from Nebula. Nebula has a roadmap that promises still to use blockchain, in some manner, as well as a token, purportedly, but the company’s co-founder and CEO admitted recently that they are still trying to figure out their business model. Nebula has opted out of a token sale, dubbing it a token generation event, which they leaked would only allow people that make $50k USD able to buy into the project.

More recently, they have wavered on whether there will be tokens at all, saying that users will earn “credits” which are used to buy items on their website. Finally, if they do pursue a token-powered platform, their tokenomics model fails to deliver a convincing case for how they can make money with their product. Their investors must have recently realized this as now Nebula claim they will essentially copy the 23andMe model of selling users’ data to pharma on their behalf, with the minor innovation of allowing their users to decline sales, but not share in
the rewards. That may not be something they are worried about as it seems more and more likely that Nebula will be a loss-leader intended to help them sell Veritas tests.

Finally, their product, which is described in their first white paper very ambitiously, is now diverging from that description, based upon their most recent code release. Looking at what they are doing, it seems the cryptographers and computer scientists are viewing this like a thesis project, and have some still very theoretical ideas about how to protect the data, none of which appear to us to be scalable, and none of which are nearly mature enough to be able to release as an actual product. They are very likely 6 to 12 months away from a useful product if their current approaches are not dead-ends. Their recent “release” was little more than a website for taking orders on testing services, and beginning to fill in profiles.

Shivom

Shivom launched their ICO without a prototype this past summer. They did everything “right” in hyping their token sale, raised what was then around 35 million USD worth of ETH (now worth about 9 million USD due to the fall of ETH since) and likely have less than 10 Million USD on hand considering their burn rate, rapid and numerous hires, as well as bounties and commissions to ICO advisors.

Shivom also faces some legal issues as one company that helped promote the sale in Australia is being sued for 2 million, and recently Shivom’s registered agent in the Isle of Man, where the project is incorporated, resigned due apparently to the terms of their engagement as agents, which suggests that the Australian case has an influence and may breach their contract. Moreover, Shivom claims to be cobbling together an alpha rapidly, but we believe their approach is flawed. They are supposed to deliver on some MoUs they signed for pilot projects in Africa and India in November 2018, and if those fail because of a substandard product or other reason based on the foregoing, they are likely out of contention completely.

The Future:

The Gene-Chain needs lots of users and lots of data. With nearly 7 million customers of direct-to-consumer genetic testing in the market and able to access their raw data, our task is to educate them on why and how to move data onto the Gene-Chain, take control, and monetize it for themselves. Our goal is a 1% conversion rate per year. In our first year, we are aiming for just .5%. We currently have nearly 600 files, within the first 2 weeks of launching, and many are being indexed (others must await new parsers).

A massive consumer marketing effort is needed to continue to grow these numbers, and is being undertaken in its earliest stages already. On the “buy” side, we will continue to engage in
serious marketing efforts to teach and familiarize researchers with the platform. We will leverage some of the coming partnerships for this, and likewise nurture relationships with key figures in the genetic research area and figure out how to best get them involved in the marketplace, buying data, and helping us to promote and sell the marketplace to the researcher community and pharmaceutical companies. Now that we have a demonstrable, fully functional and useable platform, every effort is being made to get buy in and participation from DNA sellers, buyers and potential marketplace partners whose projects, products, services and values are aligned with the Gene-Chain ecosystem.

Current Partners

Even as we seek to grow our marketplace, we are improving the Gene-Chain and the user experience. Several upgrades and enhancements are on the roadmap, including expanding user-supplied profile data to make it even more scientifically valuable for data buyers, and providing additional currency options for people to do business on the Gene-Chain.

While the DNA token works as the currency of the platform, researchers and data sellers without cryptocurrency experience need to have easy entry-points for doing business, so the token must be able to be withdrawn for its publicly-tradable version (DNA, which is available as an ERC20 token on numerous exchanges) and data buyers who are unfamiliar with cryptocurrencies must have easy access to the token through fiat currencies and greater accessibility on exchanges.
Our tokenomics model requires EncrypGen to maintain a stock of the erc20 token to provide to customers who wish to buy tokens directly from us and cash them out to exchanges. EncrypGen will go to exchanges to replenish that supply as our company supply runs low. The flow and volume of the token in the open market will benefit data sellers who wish to cash out their tokens themselves on exchanges. It will become ever easier for buyers and sellers to access the currency of the platform, and over time they may well decide to hold the token itself as store of value for genomics, which will become an increasingly valuable component of individual personalized medicine.

We envision an ecosystem of individuals (data sellers), researchers and pharma labs (data buyers) and our various health science related marketplace partners who share common goals of advancing science and medicine that enables all to do business with ease and fluidity. Users of other health blockchain platforms, like those of our partners Emrify and HeathWizz will incorporate their Gene-Chain data into a personal health wallet, with DNA as but one of the currencies in it. The DNA token is already being used to purchase DNA testing kits from our marketplace partners and will become the currency for an entire genomic blockchain ecosystem. The Gene-Chain platform will likewise become the infrastructure for a global genomic data ecosystem, facilitating commerce, ownership, individual personalized medicine, and a new age of genomic science and medicine. With active participation from buyers, sellers and partners the Gene-Chain ecosystem will accelerate scientific discovery and help find better treatments and cures for illnesses and diseases that affect millions of families annually.