

# NAVIGATING THE FINANCIAL MINEFIELD OF GENETIC TESTING

Helping patients keep their out of pocket costs affordable while getting the testing they need

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# OVERVIEW OF TYPES OF MITO CENTRIC GENETIC TESTING

- Nuclear Genes
- MtDNA Genes
- Sample types
  - Blood
  - Saliva/Swab
  - Tissue (most important for mtDNA in some cases)

# LABORATORIES WITH MITO EXPERTISE

- Baylor
- GeneDx
- Variantyx
- Blueprint
- Smaller academic aabs (Columbia, Penn/CHOP, etc)
- If a lab does not have the capability to do mtDNA, probably best to avoid them (This is my opinion only!!)
- Labs with a robust data base in this space can provide a more comprehensive interpretation of the data.

# RESEARCH VS CLINICAL TEST AND “FREE TESTS”

- Research tests are usually no charge, but they (in most cases) cannot be used to guide your treatment. (CLIA vs. Non CLIA research lab)
- In many cases, researchers will not even share the results with the referring provider.
- Clinical diagnostic tests are used to guide treatment decisions specifically for the patient/family and most labs have you sign an informed consent that allows the data to be used for research purposes
- Free or “sponsored” testing.
  - Nothing is “free”
  - The companies sponsoring (paying for the test) do it so they can monetize your DNA.
  - Not nefarious, but also not transparent. Sometimes it is the best option.

# DTC TESTING

- Direct to Consumer genetic testing (23 and me, Ancestry, etc)
- This is **non-diagnostic** from a clinical perspective and should be viewed as entertainment only.
- BRCA example
- European Journal of Human Genetics published a review of DTC testing on 10/12/22: “Research by Tandy-Connor et al. [43] revealed that DTC-GT results that showed a positive result for a pathological gene variant had a false positive rate of 40% after performing accredited confirmatory testing, contributing to the basis of these concerns.”

# TYPES OF INSURANCE, COVERAGE, COST

- Three main categories of insurance
  - Medicaid (State Run)
  - Medicare (Federal)
  - Private insurance (BCBS, United, Aetna, etc)
  - Each have their own testing coverage guidelines.
  - Generally speaking (regarding Mito pts) Medicare is the worst (no coverage, no ability to do a prior auth, no ability to appeal). If you have medicare it is usually best to explore cash pay options with the various laboratories.
  - Medicaid is State by State dependent. Publicly available guidelines. Allow Prior Auths, allow appeals in some cases.
  - Private Insurance tends to be the best In this space (you are an actual customer) Allow prior Auths, allow appeals (written/peer to peer, etc). However, also know that your insurance company is not in business to pay for your healthcare...they are in business to NOT pay for your healthcare.

# IN NETWORK/OUT OF NETWORK AND DOES IT MATTER?

- As stated earlier, Medicare will not (usually) cover this type of testing so network status is irrelevant (in most cases). There are exceptions with Medicare Advantage plans (that acts more like private insurance)
- Medicaid: It is important for a laboratory to be in network for a state Medicaid plan, otherwise most if not all Prior Auth requests will be denied for being out of network. Check with the laboratory that your state Medicaid is in network before proceeding.
- Private insurance: There are benefits and drawbacks to a lab being in or out of network with a private insurance.
  - Deductibles are generally lower for in network labs.
  - Much easier to get a Prior Authorization for testing if you are in network.
  - Contract restrictions (PAP, Cigna, BCBS Federal)

# BENEFITS INVESTIGATION

- A number of labs will do what is called a benefits investigation to determine your expected out of pocket cost prior to running the test.
- Ask about the BI process.
- Some labs require a Prior Authorization to move forward with testing, others do not. In the cases where a Prior Auth is required, the credentials of the physician can determine if a test is covered. Most insurance companies will not pay if a complex test is ordered by a PCP (or equivalent).
- In the case of not requiring a prior auth, labs will limit your out of pocket responsibility to your unmet deductible, copay and co insurance.
- Some labs will do this (Benefits Investigation or "BI") as a courtesy to the patient and the doctor, others will require the office/clinic to do it themselves. If the clinic/office has to do it, it may not be completed. It is not their job! They are in business to provide medical care, not to ensure a lab gets paid.

# BALANCE BILL VS NO BALANCE BILL

- Certain labs will balance bill you and some will not. Please find out!
- Balance Bill: The laboratory will bill you the balance of what your insurance does not cover.
- NO balance bill: The laboratory will tell you what you owe prior to initiating testing.
- Of note: It is illegal to balance bill Medicaid. Example: If Medicaid reimburses \$1.00 for a test, the laboratory must accept that and can not bill the patient anything. However, if Medicaid does not pay anything, the lab may bill the patient the full amount of the test (or suggest cash pay/pay over time options).
- Also, if testing is done at an institution/in patient setting, the laboratory will not be allowed to bill insurance and all billing will be handled by the hospital. Most of the time the hospital will have an up to 300% mark up on the cost of a test! Please ask to speak with a Financial Care Counselor!!

# CASH PAY AND PAYMENT ARRANGEMENTS

- In certain cases, the cash pay option may be the most affordable. Make sure you inquire about this option.
- Most labs will work with you if you would like to enter into a payment plan.

# KNOW ALL OF YOUR FINANCIAL OPTIONS

- Most times, your healthcare provider will not be able to tell you the specifics of the financial component of your genetic testing.
- Ask for contact information on their preferred lab and do your due diligence. Your healthcare providers do not know the financial policy of every lab (not their job!). If you can reach out to the lab directly, you will get quicker, more accurate answers.
- Inquire about financial assistance programs provided by the laboratory. Most have generous programs to reduce your out of pocket based on income and household size. Some may even reduce your out of pocket to \$0.00!
- This is not a static environment and policies change all the time. Please always ask questions/demand concrete answers on what your out of pocket will be!

# RESOURCES

- MitoAction.org
- Mitochondrial Medicine Society (MMS) [www.mitosoc.org](http://www.mitosoc.org)
- UMDF.org
- [Dave.Keane@Variantyx.com](mailto:Dave.Keane@Variantyx.com) 404-808-1476

QUESTIONS??