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Genetic carrier screening: an interview with Don Hardison, CEO of Good Start Genetics

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Interview conducted by April Cashin-Garbutt, MA (Cantab)

insights from industry

Don Hardison

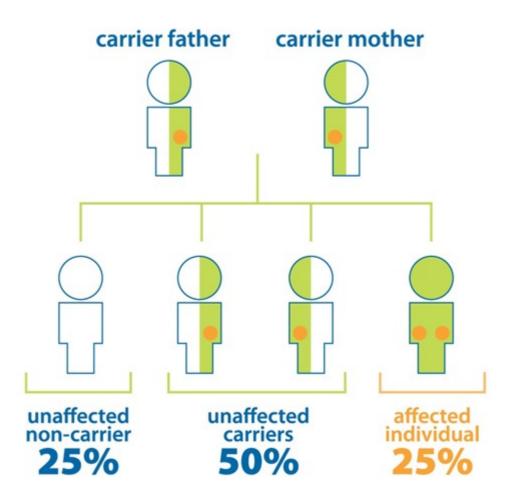
CEO of Good Start Genetics



What is genetic carrier screening and what does it mean to be a carrier?

Carrier screening provides you and your doctor with information about your risks of having a child with a serious genetic disease prior to or during pregnancy. Although most babies are born healthy, there is a small chance of having a baby with a severe genetic disease. Carrier screening helps determine what this chance is specifically for you.

AUTOSOMAL RECESSIVE INHERITANCE



Everyone has two copies of each gene – one from each parent. If you are a carrier, one of your genes has a mutation which may cause it to not work properly. Carriers for most diseases still have one working copy of the gene, so they typically do not have any health problems associated with carrying a mutation. Therefore, many people can be carriers of a disease-causing mutation without even knowing it.

What are the main reasons why people have carrier screening?

People have carrier screening for many reasons, including if they are planning a pregnancy, have a family history of a genetic disorder, are at an increased risk for a specific condition based on ethnicity or would like additional information on reproductive risks.

How do you know whether you should have genetic carrier screening? Are there any symptoms of being a carrier of a genetic disease or any particular factors that make you more likely to be a carrier?

Anyone can be a carrier of a genetic disease, even if no one in your family is affected. Most people don't know they are carriers until after they've had a screening because carriers don't have symptoms.

The chance of being a carrier is based on your ethnic background and family history; however, some diseases, such as cystic fibrosis, are fairly common regardless of these factors.

What are the main genetic diseases that can be screened for?

Good Start Genetics provides carrier screening for all 23 disorders recommended by the American Congress of Obstetricians and Gynecologists (ACOG), the American College of Medical Genetics and Genomics (ACMG) and by national Jewish advocacy groups. This includes cystic fibrosis, sickle cell anemia, Tay-Sach's disease and others.

Do you have a choice over which diseases are screened for?

Carrier screening may be ordered for you based on your ethnic background because some genetic diseases are more common among certain populations. Some genetic diseases, such as cystic fibrosis, spinal muscular atrophy and fragile X syndrome, are relatively common and carrier screening is recommended regardless of your ethnic background.

(To better understand which diseases may be more common within your ethnicity, <u>view this</u> carrier screening information brochure provided by Good Start Genetics.)

If someone has a rare disease or knows of a family history of a rare disease, how can they find out whether genetic screening is possible for the condition?

Two professional societies, the American Congress of Obstetricians & Gynecologists (ACOG) and the American College of Medical Genetics and Genomics (ACMG), as well as national Jewish advocacy groups have published recommendations for routine screening. Good Start Genetics offers screening for all society-recommended diseases. To view the full list, click here.

How is carrier screening carried out and how long does it take?

Carrier screening is done through a simple blood or saliva test. After your doctor decides which tests are appropriate for you, he or she will draw 1-2 tubes of blood or request a small saliva sample and send them to the lab for testing. It typically takes about two weeks to get your test results.

What happens once you are given the results? In particular, what happens if both partners test positive for the same disease?

If you are a carrier, the next step is to have your reproductive partner tested. Being a carrier of a genetic disease generally does not affect one's individual health. However, being a carrier does mean that there is an increased chance for your children to have the disease.

Even with two positive partners, there is still only a 25 percent chance that the child will be affected.

Does Good Start Genetics offer counseling to patients?

Good Start Genetics offers professional genetic counseling to patients regarding testing and results. Genetic counselors are specially trained healthcare professionals who have extensive knowledge about genetic diseases and how they are inherited. A genetic counselor can also help you understand your reproductive risks and options for your reproductive care.

Is carrier screening covered by insurance in the US? What is the position in other countries, such as the UK?

Carrier screening is often covered by insurance, even if other aspects of reproductive healthcare, such as IVF, are not covered. Good Start Genetics has many programs in place to help limit the out-of-pocket expenses for patients without insurance coverage for this testing.

What do you think the future holds for genetic carrier screening?

Good Start Genetics is rapidly establishing itself as a leader in the field of reproductive health. As we continue to grow this year and beyond, I want us to reach and help more women with their reproductive health and offer our high quality services to help them make intelligent, empowered choices.

We'll be launching important new products to serve the reproductive health medical community as well as their patients in the coming months.

Where can readers find more information?

Visit goodstartgenetics.com for more information or follow us on Twitter https://twitter.com/good_start_gen





About Don Hardison

Don Hardison is the President, CEO and a member of the board of Good Start Genetics. Don is an executive with broad private and public company backgrounds in both emerging and Fortune 500 companies.

Prior to joining Good Start Genetics, he was at Laboratory Corporation of America Holdings (NYSE: LH) in Burlington, North Carolina, where he served as an Executive Vice President & Chief Operating Officer.

Don has served as President, CEO and Director of EXACT Sciences Corporation (NASDAQ: EXAS), an applied genomics/biotechnology company focused on the early detection of cancer.

Over the past 30 years, he also has worked as a Managing Partner of OnTarget, a sales and marketing consulting firm, and has held numerous leadership roles at Quest Diagnostics and SmithKline Beecham Corporation. He holds a bachelor's degree from the University of North Carolina, Chapel Hill.