

COMMENTARY

Robert C. Green: By sharing their genetic risks, Hemsworth, Jolie are raising awareness of testing

By Robert C. Green

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Actor Chris Hemsworth, who appears in National Geographic's "Limitless" series, reacts to fans at PopCon Middle East in the United Arab Emirates on Nov. 11, 2022. (Kamran Jebreili / AP)

FEEDBACK

When actor Chris Hemsworth, aka Thor, God of Thunder, agreed to host a National Geographic series about extending the human life span, he didn't expect to discover a genetic risk of his own. But that's what happened as Hemsworth revealed on an episode of "Limitless" that he carries a common change in the APOE gene associated with an increased risk of Alzheimer's disease.

Hemsworth almost opted to keep his finding private, but in the end he decided to go public, a decision reminiscent of actor Angelina Jolie, who in 2013 revealed that she carries a change in the gene called BRCA1 that confers a high risk for breast and ovarian cancer. Jolie, another actor whose roles have included superheroes on screen, chose to have risk-reducing surgeries and inspired many to get similar testing, and her example sparked broad discussion about the power of genes to offer predictions about the future risk for cancer.

Now, the complementary experiences of these two "superheroes" offer a chance to clarify a few key principles around genetic testing for the public.

Genetics is not a crystal ball

Most genetic changes, including the ones discovered in Jolie and Hemsworth, do not guarantee that the individual will develop the disease.

For example, with the BRCA1 gene change that she had, Jolie's risk of breast cancer before surgery was increased from a lifetime risk of 13% to between 55%-72%. With his APOE gene changes, Hemsworth's risk of developing Alzheimer's disease is higher than most, but by some estimates it is still only 30%-55% so the odds are still good that he will avoid that fate. Most genetic information helps estimate risk, but does not signal a preordained outcome.

Treatable and untreatable conditions

Some people want to know "everything," but others only want to know genetic risk information if you can "do something about it," by which they usually mean a medical intervention to prevent or slow the disease in question.

In 2013, I helped create an official list of what is now 78 genes for [“treatable” conditions](#) that has become the basis for many screening programs using genetics. The APOE gene for risk of Alzheimer’s disease is not on that list but the BRCA1 gene is. So if people want to learn their risk for treatable cancers, treatable heart conditions and other treatable possibilities, but would prefer to avoid learning about their risk for untreatable conditions like Alzheimer’s disease, that’s an easy option.

Surprisingly, many people want to know their gene status for untreatable conditions like Alzheimer’s disease for life planning or in order to be first in line for new clinical trials or treatments that may emerge in the future. The discovery of personal genetic risk is less distressing than people imagine and has a way of galvanizing both passion and progress.

Technology matters

Popular direct-to-consumer genetic testing companies such as Ancestry or 23andMe are to be commended for demystifying and democratizing genetics using array technology that can detect some DNA changes but not others.

For example, 23andMe screens for the three most common breast and ovarian cancer gene changes, which has undoubtedly saved lives; but it does not report on over a thousand other such changes in the same genes. The newer technologies of gene sequencing are more expensive but can read every letter of one or many genes, allowing the detection of many more people with changes that put them at risk for hereditary forms of cancer and heart disease.

Genetic risk and longevity

The quest for greater longevity is having a moment in our culture. Ironically, Hemsworth's experience with genetics in the context of the National Geographic show "Limitless," a show that highlights physical challenges to combat aging, reminds us of the underappreciated fact that all anti-aging efforts should be anchored first in the avoidance of premature and preventable death.

We have estimated that well over 2.5% of Americans carry genetic markers for elevated risks of treatable cancer and heart conditions that are easily detectable by cost-effective medical sequencing. Yet doctors and health care systems have been slow to adopt preventive genomics because physicians are not confident about ordering and interpreting such tests and most proactive genetic testing is not yet reimbursed by health insurance.

Hemsworth and Jolie play superheroes in films but it takes exceptional real-world courage to share their own health issues. Their generosity is accelerating awareness and acceptance of a future where we do not wait to respond to the ravages of so many diseases but rather anticipate, predict and prevent them through genomics.

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