

Introducing the



# Voluntary Healthcare Research Benefit

*A free benefit designed to bring the promise of medical research to everyone.*



Advancing medical research; developing new medications and medical devices; and helping providers learn how to best deliver care, are things we all support. That's why it's not surprising that, given an opportunity, most patients choose to participate in, and contribute toward, medical research for altruistic reasons; to access new, leading-edge treatments from pioneering providers; or to focus more attention on their illness. The **HERO Voluntary Healthcare Research Benefit** is a no-cost benefit that provides an opportunity for employees, family members and caregivers to

- participate in a *healthplan study* to help evaluate new medical technologies and innovations;
- enroll in a *clinical-research-as-a-care-option* program to focus more resources on their care;
- earn a *genetic (DNA) test* to guide them and their physicians for the rest of their life, and
- create a *health dataset* for themselves and to share with care providers and researchers...

all, while earning funds and rewards to apply to deductibles, coinsurance, bills, tuition, etc.

## The Importance of Medical Research

While it is true that we are living longer, we are also getting sicker. Indeed, the number of people age 65 and older having four or more medical conditions is expected to *double* over the next fifteen years...and nearly one in ten (~ 30 million) Americans have one of 7,000 rare diseases, only about five percent of which have treatment options of any kind, other than symptom management. Moreover, ~ 70 million Americans will be over the age of 65 by 2030, many having an expectation of living two decades longer. Most in this group will expect, if not demand, medical treatment options beyond the usual and customary, the goal being not merely an absence of disease and infirmity but to improve their health-related quality of life and well-being for as long as possible.



To satisfy the needs of these substantial populations, an enormous investment to advance science and medicine is necessary to discover new medical strategies, treatments, devices and innovations. Medical research plays a vital role in advancing potential new treatments from the research bench to the clinic, acting as the backbone of modern evidence-based care; demonstrating efficacy, safety and value; and helping to prevent, detect, treat and manage disease and illness. Understanding this, the investment needed is being made with an increase in medical research and development expenditures to \$200+ billion over the next five years, a 30% increase in less than ten years. Despite this, in the past five years less than half as many new drugs have reached the market versus the previous five. In great part, this is due to the miserable failure of the present research study infrastructure and model. However, notwithstanding scientific advancement accelerating at a rate that has not been seen before, there is an urgent worldwide need to conduct many more clinical trials and medical research studies, on both old and new diseases. Unbeknownst to most, there has been a slow motion crisis brewing in medical research: an inability to recruit and retain research participants; it is a critical challenge facing scientists, health innovators and researchers worldwide, and one that impacts all of us as more and more research studies get scrapped.

## **The Little-Known Crisis in Medical Research**

Medical research studies focus on drug development and usage; patient, caretaker and provider behavior; surgical procedures and medical devices. There are some 125,000 active medical research studies in the United States alone; with 15,000 new studies started last year alone. Half of all studies are observational in nature. And, while patient participation is crucial to advancing medical research, nearly 20% of all clinical research studies are prematurely terminated due to participation shortfalls. In fact, today, we need more than 50 million research participants to complete studies already underway in the U.S. alone. This is a critical problem as it is estimated that a whopping 80% of all research study sites are unable to recruit sufficient numbers of participants; and about 20% of drug studies enroll less than half of their target number of participants *after three years*. As a result, many studies take 2 - 3 times longer to complete than planned, with only 6% completed on time. It is therefore not surprising that fewer than 10% of the drugs that start the clinical trials process eventually earn FDA approval. This situation has created a world-wide crisis among medical researchers.

## **The Good News**

Although fewer than 2% of Americans participate in clinical trials, it isn't for a lack of interest. Recent surveys indicate that more than 70% of those sampled say they would be "interested" or "very interested" in participating in a medical research study if recommended to do so by their doctor. The reality is however, that most patients are simply unaware of clinical research opportunities. National surveys show that some 80% of respondents believe that it is important to be made aware of the opportunity to participate and more than 85% believe a discussion about medical research and clinical trials should be a routine part of standard care.

Multiple surveys of research study participants evidence a very high level of patient satisfaction with them. More than 95% of those surveyed said participating improved their health knowledge, interest and involvement in their overall health care; that their overall quality of care was significantly better or improved; and that it reduced the overall cost of their health care, decreasing both complications and hospital (re)admissions. Moreover, the overwhelming majority of clinical research patients appreciated the increased attention and "VIP" treatment (more frequent visits, in-depth health assessments, focused attention on their condition, etc.) they received by participating and most appreciated the research sponsor's determination to find new treatments that could benefit them. Further, participants expressed greater confidence that their routine medical care was being augmented and provided by experts who were knowledgeable and up-to-date on the best available treatments.

Below are the testimonials of actual clinical research study participants, in their own words:

*"I am more cognizant of my condition and my motivation has increased tremendously."*

*"Better information and a better understanding of my A1C. Education that I was not expecting."*

*"Being better aware of how to manage my condition. Gives me the enthusiasm to help myself get better."*

*"It made me much more motivated to work on my diabetes."*

*"The way that we monitor and do things is much more frequent that it was with my regular doctor."*

*"The whole system has done me a world of good."*

*"Study participation has allowed me to manage my diabetes better than I ever have before."*

*"They even include my spouse into the meetings and care plans."*

*"What it's done has made me more regimented. I was never near as regimented. It keeps me engaged."*

*"Numbers have never been better, even if I was paying, it would be worthwhile to me."*

These statistics and endorsements provide powerful evidence of the value of joining in clinical medical research and a compelling reason to learn more about how you, a family member or caregiver may benefit by doing so.

## Putting the *HERO* Voluntary Healthcare Research Benefit to Work for You

Participating in medical research can bring with it many patient, provider and caregiver benefits. It can help you to play a more active role in managing your own health care; be a source of empowerment and hope for those who can gain from it; and be a viable care option that may lead to enhanced outcomes, patient satisfaction and value. Joining in medical research also expedites the drug and medical device development process and brings more innovation to the market faster. Your providers will benefit by enhancing their knowledge about the latest therapies, technologies and practices before they come to the market; and learning new means by which to best deliver your care. Below are just three ways you can use the *HERO* Voluntary Healthcare Research Benefit.

### 1. Create a Personal Health Dataset for you, your medical providers and medical researchers.

New technology and legislation now makes it easy for *anyone* to collect, securely store and share their health data; something that can be helpful to you, your caregivers and medical providers as well as researchers looking to advance medicine and science. Regardless of your present health status, *everyone* can create a “personal health dataset” (medical/pharmacy claims data; medical records, lab and radiology results and genetic data). Plan participants can share their health datasets with researchers and earn money and benefits, often several times a year. As described below, these benefits may include a no-cost medical-grade DNA test and *lifetime* access to sophisticated, but easy-to-use, AI-based web technology that will enable you and your physicians to “query your genome” to learn how your genes may impact everything from how you metabolize medications to what foods are good and not good for you; and many more things as science advances in the future. Health datasets shared by patients having a rare disease may be especially valuable... and, you should know, that we will *never* sell your health data to pharmaceutical companies for financial gain, like most of the recreational- and ancestry-oriented genetic testing companies do.



#### *Genetic Testing and Clinical Research*

*Recognizing their great value, more and more pharmaceutical, academic and foundational researchers are incorporating genetic (DNA) tests into their clinical research study regimens. Genetic tests explore a person’s DNA to identify changes in chromosomes, genes, or proteins and are used by physicians for diagnostic, prognostic and predictive purposes. Genetic tests can confirm or rule out vulnerabilities to inherited diseases; or help determine a person’s chance of developing or passing on a genetic disorder. Pharmacogenomic (PGx) tests determine the influence of genetic variation on drug response to determine which and what dosage would be the safest and most beneficial given the person’s unique DNA (so that they don’t have to try several medications before they find the right one). A perfectly healthy person can also benefit from obtaining medically actionable genetic data to learn more about what they can do to remain healthy or to become aware of what’s to come for them health-wise so that they can take action to prevent certain disorders for which they might be more susceptible (from simply wearing more sunscreen to undergoing a preventative mastectomy).*

### 2. Participate in a *Research Consortium*-sponsored *bench-to-bedside* research study or survey.

Remarkably, on average, it takes 17 years for a new medical technology to move from development to widespread clinical use. In great part, this is because “translational” research that looks to provide evidence for benefit plan sponsors to help them determine which new technologies/innovations to adopt and cover is rarely conducted. Our bench-to-bedside studies focus on assessing the ROI, value vs. the standard of care, and health outcomes of *proven* medical technologies and health innovations *in clinical use*. Easy to participate in, our studies help to rapidly determine “if, when and how” to include new technologies and advances in your plan and are conducted by independent researchers, MDs and scientists from top universities/medical foundations.

### 3. Enhance your routine medical care by considering a *Clinical-Research-as-a-Care-Option program*

Chances are you've taken a prescribed or OTC medication sometime in your life: if you have, you've benefited from clinical research. Unlike bed-to-bedside *translational healthcare* research, *clinical medical* research (aka "clinical trials"), and similar forms of medical research, focus on the development of new drugs seeking FDA approval; new ways to deliver approved drugs; alternative medicines, vitamins and herbs; new tests and technologies to track and manage disease; procedures that relieve symptoms; and other ways to prevent, detect, treat or manage disease and illness. Clinical research is typically sponsored and conducted by universities, medical foundations, biotech/pharmaceutical companies and medical device manufacturers.

Unfortunately, operating as if it has been in an unrelated industry, clinical medical research has been largely disconnected from the routine medical care delivery system, so much so that for decades most doctors have been unaware of available clinical research opportunities. As a result, few physicians can effectively offer their patients the opportunity to participate in clinical research as a care option programs that could be of great help to them. The good news is that leaders throughout the healthcare ecosystem now appreciate that the gap between *healthcare* and *research* needs to be bridged and, as such, a cultural shift has begun in support of integrating clinical research into patient care as a care option; something that is both warranted and overdue.

The concept of *clinical-research-as-a-care-option* (CRAACO) is an uncomplicated, straightforward one. Essentially, it is the coordinated augmentation of a patient's routine health care with expert care obtained by participating in a clinical research study. Once looked upon by patients and physicians alike as a risky decision, last resort or far-fetched hope, participating in clinical research is now seen as a legitimate care option to be made available alongside traditional treatment methods. Because communication and information sharing has increased, and patients have become more knowledgeable about their own health care, public perception toward participating in clinical research is shifting. Today, it is now increasingly more apparent that clinical research should be considered as a care option and extension of one's healthcare plan. The value of integrating clinical medical research into a patient's overall continuum of care can be enormous; especially for patients who suffer from chronic or rare diseases. Participating in clinical research can offer you access to the latest medical technologies, treatments and state-of-the-art care. Rather than being limited to only traditional treatments, patients are made aware of and given an opportunity to consider all available care options. Participating in clinical-research-as-a-care-option can focus more attention on your illness and provide you with the potential to receive no-cost, leading-edge care and attention from pioneering providers.

A cornerstone of clinical-research-as-a-care-option is the preservation of the doctor-patient relationship. This is achieved by facilitating the ability for treating physicians to bring clinical research opportunities directly to their patients by expanding the traditional clinical research setting to include local medical practices. Indeed, rather than requiring clinical research participants to go to regional medical centers or university research hospitals they can often obtain care at their physician's office, or even while at home, under the care of their trusted physician, and guidance of an expert medical researcher. By bringing clinical research expertise, knowledge and operational know-how to the physician office to help augment standard clinical care, healthcare physicians and their patients are engaged who may not have otherwise participated in such research.

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The **Research Consortium HERO** staff assists with the creation of patient health datasets and participating in our bench-to-bedside studies and clinical research. We provide patient, caregiver and provider education and guidance, as we know that engagement is recognized as a vital element in good healthcare delivery. Indeed, mounting evidence confirms that it leads to improved medical outcomes and lower costs. Our Guides assist plan participants in the creation and monetization of their health data. Our Shepherds steer participants through our translational research studies. Our Navigators match patients with appropriate clinical research studies and direct them through the clinical-research-as-a-care-option to ensure continuity of care.

## Who Benefits from the **HERO Voluntary Healthcare Research Benefit**



Karen, a college student, suffers from Irritable Bowel Syndrome, which affects 40 million Americans. Indeed, it is the focus of more than 130 research studies. The **HERO Voluntary Healthcare Research Benefit** helped Karen to:

- 1) obtain a no-cost PGx test to determine which medications work best for her DNA;
- 2) match her with a clinical research trial to test a new IBS drug (and earn \$500);
- 3) assist her doctor with introducing the new medication into her care regimen; and
- 4) create a *health dataset* for her to support medical research (and earn \$400/year).

Ed, age 47, has NASH, a disease that causes fat build-up in the liver. Some 20 million Americans suffer from NASH...and, because its symptoms are masked, most don't know it. The **HERO Voluntary Healthcare Research Benefit** enabled Ed to:

- 1) help him navigate a clinical research trial re: a new NASH drug (and earn \$750);
- 2) create a *health dataset* to share with drug researchers (and earn \$950/year); and
- 3) obtain a no-cost, medical-grade DNA test that he can access and query for the rest of his life, as science evolves over time, with an easy-to-use, web-based tool.



Zach, age 28, thinks he's "okay", but he isn't. He has been in and out of "programs" for bi-polar disease and prescription drug abuse; trying one medication after another to no avail. Through the **HERO Voluntary Healthcare Research Benefit** Zach:

- 1) got a psychiatric-focused pharmacogenomic test to determine which medications work and don't work with his unique DNA, guided by highly-skilled experts from one of the leading national genetic medicine practices; and
- 2) benefited, with his doctors, from having the test results interpreted by a geneticist.

Mario, age 85, is amazing: he has smoked since he was a teen, yet has enjoyed great health. His blood pressure, BMI and cholesterol are perfect and he's *never* taken a medication. Mario used the **HERO Voluntary Healthcare Research Benefit** to:

- 1) obtain a medical-grade DNA test that he can query forever via an easy-to-use app (sponsored by a pharmaceutical company wishing to study why he is so healthy);
- 2) join in iPhone-based surveys to help his pharma researchers (and earn \$500); and
- 3) create a *health dataset* to share with the pharma researchers (for \$1,000/year).



Esther and Joel are newlyweds looking to start a family. While a person, on average, carries 3 - 5 genetic mutations, due to factors owing to their ethnicity, *this couple* is at high risk of passing on an inherited *recessive* genetic disorder. When both parents are carriers, the couple has a 25% risk of having an affected child and a 50% risk that it will be a carrier. With the **HERO Voluntary Healthcare Research Benefit**:

- 1) Esther and Joel both had no-cost, DNA tests to determine if either is a carrier; and
- 2) a pre-natal DNA test to see if the baby had birth defects or is a carrier.

The parents of these exceedingly cute twins, knowing that their lifespans are likely to be at least 90 years, used the **HERO Voluntary Healthcare Research Benefit** to:

- 1) have both children DNA tested, at no cost, in return for sharing their test results with academic researchers having a desire for long-term health data on twins; and
- 2) create a *health dataset* for each child, that is automatically and effortlessly updated and furnished to medical researchers (enabling the couple to earn more than \$20,000 -- over several years -- toward the cost of their college education).



Poor Luke: he's one of the 1.3 million Americans annually to visit the ER due to an avoidable adverse drug event (ADE); *and* one of 400,000 to be hospitalized. He, like half of all seniors, is on five or more meds, at least one of which is inappropriate. Despite many ER visits, he has never had a DNA test to determine which Rx's are causing his ADEs. Using the **HERO Voluntary Healthcare Research Benefit**, he:

- 1) got DNA tested, with guidance from a top national genetic medicine practice; and
- 2) had his physician speak to a genetics expert to help adjust his medication regimen.

Bill and Mary, married 52 years, are both age 75. Sadly, Mary was just diagnosed with Alzheimer's, a largely inherited disease and the 6th leading cause of death in the U.S. Alzheimer's affects one in three seniors, or six million Americans. They used the **HERO Voluntary Healthcare Research Benefit** to:

- 1) arrange for Bill to take part in (and benefit from) virtual surveys for caregivers;
- 2) have Mary participate in a home-based clinical study to test a new drug; and
- 3) arrange for Bill and Mary's children to be DNA tested to see if they are carriers.



Julia, age 42, is one of the 8% of Americans who live with Type-2 diabetes, the 7th leading cause of death in the U.S. (at 80,000/year.). Despite being largely preventable by weight control, exercise and proper eating, the number of new cases still doubles annually. Julia used the **HERO Voluntary Healthcare Research Benefit** to:

- 1) find and navigate a diabetes-focused clinical-research-as-a-care-option study;
- 2) guide her doctor with introducing new diet guidelines into her care regimen; and
- 3) create a *health dataset* for her to contribute to research (and earn \$600/year).

## Learn More and Get Started Today

Contributing to healthcare and medical research. Enhancing your care management. Accessing new medical innovations, pioneering providers and care options. Earning extra money and benefits by sharing your healthcare data and joining in research studies. All these opportunities exist and are easy to take advantage of by enrolling in the free **HERO Voluntary Healthcare Research Benefit**. Our friendly, compassionate and knowledgeable Shepherds, Navigators and Guides are anxious to discuss each opportunity with you, your caregiver and provider.

To learn more about the **HERO Voluntary Healthcare Research Benefit**, download the **HERO** app from the Apple Store, Google Play, Amazon, [www.ResearchConsortium.org](http://www.ResearchConsortium.org) or your benefits administrator's website at [www.ABCPlanAdministrators.com](http://www.ABCPlanAdministrators.com), or reach us at (800) 123-4567 or [IWantToHelp@ResearchConsortium.org](mailto:IWantToHelp@ResearchConsortium.org).

Whether you are perfectly healthy, chronically ill or in between, *you* can benefit from enrolling in **HERO**.