# What is ADVANCENT?

Questions and answers for patients and their families





#### WHAT IS ADVANCENTSM?

ADVANCENT, the National Registry to Advance Heart Health, is a confidential, national registry, or information resource, that follows how heart patients are cared for over time. It gathers information on up to 100,000 heart patients.

ADVANCENT provides doctors with more information about how heart patients are treated.

No other source for such long-term, all-inclusive heart care information currently exists in the U.S. The goal of ADVANCENT is to better understand what treatments are most effective in helping people with weakened hearts.

ADVANCENT<sup>™</sup> is designed to provide ongoing insight about how heart patients are treated.



#### Are all heart patients in ADVANCENT?

No, only patients in participating clinics (like yours) are being enrolled. Participation is strictly voluntary. You may choose not to participate, and you will not be enrolled in ADVANCENT without your written consent and authorization. You may also withdraw from ADVANCENT at any time and for any reason.

In addition, ADVANCENT will only enroll patients whose left ventricle, the lower chamber on the left side of the heart, is pumping at less than normal capacity. This is called left ventricular dysfunction, or LVD. If you have an ejection fraction of 40% or less, you have LVD.

All of your personal data will be kept strictly confidential. Only your participating ADVANCENT clinic will have access to your detailed treatment information, and your name will never be revealed to the registry at large.

# What does ejection fraction mean?

The ejection fraction is a measure of how much blood your heart pumps or ejects. If your heart is healthy, it would usually pump, or eject with each beat, one half or more of the blood it holds. In other words, this is an ejection fraction of 50% or more. If your ejection fraction is 40% or less, it often means that certain conditions or events (such as a heart attack or other heart damage) have reduced your heart's ability to pump.

There are a number of ways to determine your ejection fraction. You can read about many of them at www.advancent.org.

# What will I get out of being in the registry?

You will have the knowledge that you are contributing to the understanding of how heart disease is treated, which will help others with your condition. Also, your clinic will have access to information that can be used in your care.

ADVANCENT shares and supports the goal of clinics across the country: to enhance patients' lives, keeping families and communities together.



## What will I need to do to participate?

Your most important responsibility is to be available to your clinic's ADVANCENT coordinator for data updates, scheduled at roughly 6, 12, 24, and 36 months after you enroll. These updates may take place through a normal office visit, a telephone consultation or through your primary care physician. Participation in ADVANCENT requires no clinic visits outside those you would normally make.

At enrollment and during data updates, your clinic will gather and update demographic, historical, diagnostic and therapeutic information regarding your condition and care.

Your data, combined with that of other ADVANCENT enrollees, will create the ongoing flow of information that your clinic — as well as the other clinics across the United States — can use for insight into the care of patients with LVD.

As knowledge about LVD and its treatment evolves, the study database will be a valuable resource for the medical community.

#### What kind of data will be collected?

Information entered in the registry includes test results, prescribed therapies, lifestyle factors and more. It is this comprehensive approach that makes ADVANCENT exceptional and unlike any other registry in the field of heart treatment.

Information gathered will include:

- Findings from your check-ups
- Laboratory test results
- Your current treatment plan (medications, implanted devices such as pacemakers, or other therapies)
- Any cardiovascular risk factors you might have, such as diabetes, high blood pressure, high cholesterol, prior heart attack, etc.
- Any changes that have been made since you began your treatment(s)

You may also have an opportunity to complete surveys on:

- Your quality of life
- Your satisfaction with your treatment(s)
- How well you are following the recommendations and therapies your doctor has prescribed for you



## What will be done with my data?

Your information will be sent to an independent organization that will manage the data. In turn, this data will be compiled with data from similar patients across the country and will be analyzed by health care professionals in order to better understand and improve the treatment of heart disease and cardiovascular care plus share best practices that emerge.

#### Will marketers contact me?

No. You will not be put on any mailing list, and there will be no solicitations of any form.

## Will it cost me anything to participate?

No. Neither you nor your insurer, if applicable, will incur any additional costs. You will still be responsible for the cost of your usual ongoing medical care, including procedures or medications that you require as part of your treatment.

All your personal data will be kept strictly confidential.

## **How long will ADVANCENT last?**

ADVANCENT is scheduled to last three years, though it may end earlier or last longer. In the event it lasts longer, you will be notified and will have the option to either continue or withdraw. Your clinic also has the right to remove a patient who is unable to meet the scheduled data updates at 6, 12, 24 and 36 months.

This comprehensive compilation of data will provide an opportunity to evaluate specific ways to manage LVD patients. As knowledge about LVD and its treatment evolves, the study database will be a valuable resource for the medical community to evaluate treatment decisions for LVD. Participating clinics throughout the United States will review the way other clinics treat LVD patients just like you. With this knowledge, clinicians (like yours) across the nation will stay in rapid touch with ongoing advances in LVD care.

