

How to Use the ACHD Clinic Directory

The fact that a clinic is listed does **NOT** mean that it meets standards for specialized ACHD care – it just indicates that it describes itself as an ACHD clinic and completed *ACHA's* survey. The clinics listed here vary greatly in size, staff training, and services offered. In addition, all the information listed is **SELF-REPORTED and UNVERIFIED**.

ACHA urges all congenital heart patients to interview *thoroughly* all ACHD clinics about the specific training, volume, and special services they offer. In using the Clinic Directory, we suggest looking at the following factors, *recognizing that no one factor defines the Clinic best for you*. We encourage you to ask your own questions and learn all you can about the ACHD clinics listed here. You can find a list of questions below.

In using the Clinic Directory, we suggest you look at the following factors:

- **Total number of ACHD patients seen per year:** Experience counts, particularly given the wide variety of defects, health problems, previous surgeries, etc., in adult congenital heart disease. However, please note that many centers submitted estimated numbers. Accuracy may vary.
- **Total number of ACHD clinics per week:** A higher number of clinics a week may reflect a greater commitment to an ACHD program.
- **Year of founding:** This may be a measure of a special interest in ACHD patients over time. However, newer centers may also offer expertise, special training, and rapidly-growing volume.
- **Background and training of director and staff:** Each program description includes information on the training and background of ACHD clinic staff. Younger ACHD cardiologists may have trained specifically in a new adult congenital cardiology program. Others will have trained as either a pediatric or adult cardiologist, but should also list specific training and background in adult congenital heart disease (for example, years of direct experience treating adults with CHD, time spent training at other ACHD clinics).
- **Clinical Services offered:** There may be particular services, such as high-risk ACHD pregnancy care or the availability of a medical social worker, which are of special interest to you.
- **Location:** Some people choose the closest center with self-identified ACHD expertise. Others choose to travel out of area. If you do not have an ACHD center nearby, you may need to travel to get recommended care. Many ACHDers use a “team approach.” After an initial consult, the ACHD specialists team with a local cardiologist to provide care.
- **Phone numbers:** You may want to call the ACHD clinic number provided to ask questions about what is offered. In addition, you may want to call other divisions (such as pediatric or adult cardiology) and ask for information about the ACHD clinic.
- **Websites:** ACHD clinic website links are provided where available. These can be helpful sources of additional information, but keep in mind that websites are a form of advertising. An impressive site may or may not reflect the quality of what is offered.

ACHD Clinic Interview Form

The following are some recommended questions to ask when seeking care for complex congenital heart conditions:

- How many full-time staff does the ACHD clinic currently employ?
- How many part-time staff does the ACHD clinic currently employ?
- I have (specific diagnosis here). Approximately how many adult patients does your clinic treat a year with my diagnosis? Approximately how many adults with congenital heart disease does your clinic treat a year? Approximately what percentage of these adults with CHD has a complex congenital heart disease?
- What is the approximate age range of your adult congenital heart patients? What percentage of your patients is in my age range?
- What percentage of your time is spent treating ACHD patients?
- What specific training and experience have you had to prepare you to treat adults with complex congenital heart disease? When? Where? How long have you been treating ACHD patients? In what context(s)?
- Do you have a nurse practitioner/nurse/physician's assistant assigned to the ACHD clinic? What percentage of her/his time is spent treating ACHD patients? What specific training/background does s/he have in adult congenital heart disease?
- Do you have an electrophysiologist assigned to the ACHD clinic? What percentage of her/his time is spent treating ACHD patients? What specific training/background does s/he have in ACHD electrophysiology?
- Do you have echocardiographer(s) assigned to the ACHD clinic? What percentage of her/his/their time is spent treating ACHD patients? What specific training/background does s/he/they have in ACHD echocardiography?
- Who is on-call for ACHD clinic patients? Is there always someone with training in ACHD care available in an emergency?
- Do you have a cardiac surgeon available with experience and competence in complex ACHD surgery?
 - a. (If yes) Who? How many operations on complex adult congenital heart disease patients does s/he perform a year? If I need an emergency ACHD operation, will I have 24-hour access to a congenital heart surgeon?
 - b. (If no) Where do you send your complex adult congenital heart patients in need of surgical intervention?
- Do you have a cardiac catheterization lab and staff available with training and expertise in adult congenital heart disease diagnosis and intervention?
 - a. (If yes) Who? How many catheterizations do s/he/they perform on complex adult congenital heart patients a year? If I need emergency diagnosis/intervention, will I have 24-hour access to catheterization performed by those trained in ACHD care?
 - b. (If no) Where do you send your complex adult congenital heart patients in need of diagnostic catheterization? Interventional catheterization?

You may want to consider asking these other recommended questions depending upon your individual situation and needs:

- Pregnancy
- Insurance
- Genetic counseling
- Financial counseling
- Therapy