

Are We Ready for the Surge of CHD Survivors?



Congenital Heart
PUBLIC HEALTH CONSORTIUM

Congenital Heart Disease (CHD) represents a medical challenge that spans the life of a patient from birth through adulthood. Due to advances in medical and surgical therapies, more than 90% will live to see their 18th birthday (Moons P, 2010). As a result, the number of adults with CHD in the US has now surpassed the number of children with CHD. There are currently more than 1.3 million adults with CHD in the US, and this prevalence is expected to increase 5% annually, resulting in a surge of survivors who need life-long specialized care (Marelli A, 2007). While the number of patients has risen, less than 25% are currently cared for in subspecialty Adult Congenital Heart Defect (ACHD) centers. Healthcare costs continue to rise and the hospital admissions for patients with ACHD have risen by 101% between 1998 and 2005. Nearly 20% of these admissions were for cardiac surgery (Opotowsky AR, 2009). Healthcare utilization and costs continue to rise, due to hospital admissions, cardiac and non-cardiac surgery, and emergency room visits. For example, with improved longevity to childbearing age, the number of high risk annual births in women with CHD is increasing. However, these women are eight times as likely to experience cardiovascular complications during pregnancy and have a higher risk (six times greater) of dying compared to women without CHD (Opotowsky AR, 2009).

There are several barriers to accessing and maintaining lifelong care. Some of these barriers have been addressed under the Affordable Care Act (ACA), (e.g., no person can be denied coverage or charged higher premiums because of a preexisting condition, and young people, including those with CHD, can remain on their parents' policy until the age of 26). Yet, significant concerns related to insurance coverage and network adequacy remain. Lack of access to appropriate pediatric and adult medical subspecialists and surgical specialists is an additional barrier. Specifically, finding cardiologists with subspecialty expertise in adult congenital heart disease can be challenging. In 2015, the American Board of Internal Medicine (ABIM) administered the first ACHD subspecialty board certification. Board certified physicians in adult congenital heart disease can now be easily identified through the ABIM. However, for the time being, there is still shortage of specialized providers with less than 200 board certified adult congenital providers to serve the approximately 1.3 million adults with congenital heart disease

Challenges of not staying in subspecialty care

- Healthcare costs are higher when patients re-enter the system requiring advanced care due to late recognition of problems
- When experiencing health concerns, inability to find a specialized healthcare provider, especially during emergencies, could result in delayed or inappropriate care
- Loss of functional capacity due to late recognition of problems

Reasons for dropping out of subspecialty care

- Lack of understanding of the lifelong nature of CHD – Patients “Felt well,” or “Were fixed,” believing they no longer needed care
- Lack of access to continuous insurance coverage
- Lack of access to quality information about providers and healthcare institutions
- Lack of local access to an ACHD provider

Opportunities for public health

- Adolescent and adult surveillance to assess patterns of access to care and resource utilization
- Public Health education and awareness for both providers and patients to support need to stay in care



Meet Lindsay

I have always had an adventurous spirit. However, having Congenital Heart Disease makes every life decision a bit more complicated. I knew that wherever I landed I had to advocate for proper medical care. Transitioning appropriately to adult care was not an option, it was a **MUST** if I wanted to fulfill my dreams of travel and adventure.

This summer, I am off to Hawaii. I find myself, once again at a place of transition in my own life. I will have to navigate a new ACHD cardiology team and once again advocate for access to specialty care. I am incredibly thankful for all those who have saved my life and all those who will continue to provide me with the best cardiology care.

Lindsay Barth

View the [ACHD Clinic Directory](#) for care options in your area.

[Temporal trends in survival to adulthood among patients born with congenital heart disease from 1970 to 1992 in Belgium.](#) Moons P, Bovijn L, Budts W, Belmans A, Gewillig M. *Circulation*. 2010;122(22):2264-2272.

[Congenital heart disease in the general population: changing prevalence and age distribution.](#) Marelli AJ, Mackie AS, Ionescu-Ittu R, Rahme E, Pilote L. *Circulation*. 2007;115(2):163-172. Accessed February 21, 2012.

[Maternal cardiovascular events during childbirth among women with congenital heart disease.](#) Opotowsky AR, Siddiqi OK, D'Souza B, Webb GD, Fernandes SM, Landzberg MJ. *Heart*. 2012 Jan;98(2):145-51. doi: 10.1136/heartjnl-2011-300828. Epub 2011 Oct 11.

[Trends in hospitalizations for adults with congenital heart disease in the U.S.](#) Opotowsky AR, Siddiqi OK, Webb GD. *J Am Coll Cardiol*. 2009 Jul 28;54(5):460-7. doi: 10.1016/j.jacc.2009.04.037.