

# #CHDCare4Life

## Congenital Heart Disease is Chronic, and Care is Costly



### Help keep this population in care and healthy

Congenital Heart Disease (CHD) is the most common birth defect, and it presents challenges that span the life course from birth through adulthood. Due to advances in medical and surgical therapies, more than 90% of those with CHD will live to see their 18<sup>th</sup> birthday.<sup>i</sup> 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 by 5% annually.

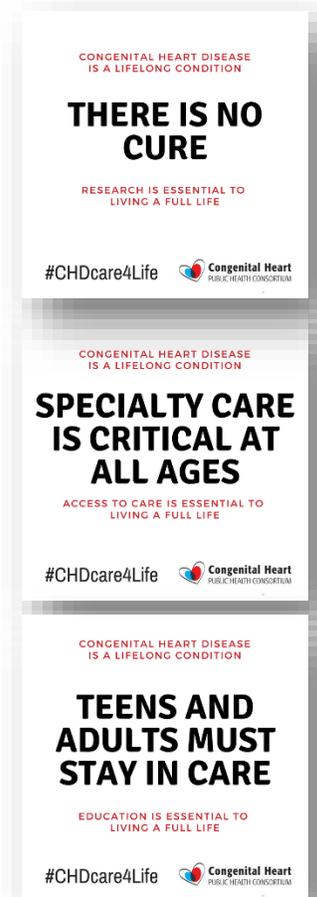
The course of CHD is variable, with long periods of good health interrupted by episodes of significant illness caused by abnormal heart rhythms, heart failure, stroke, and problems with other organ systems, such as liver, kidney, and behavior or mental health issues.<sup>ii</sup> This results in periods of high health care utilization. Individuals with CHD who don't maintain routine care during periods of wellness may present to the Emergency Department quite ill, resulting in even higher resource utilization.<sup>iii,iv</sup> Keeping people with CHD in care throughout the lifespan may prevent such intermittent episodes of acute illness and high costs.

### Healthcare utilization trends

- Nearly 2.5 million in the US currently have a CHD, over half of whom are adults.<sup>v</sup>
- Nearly 40,000 patients of all ages are admitted to the hospital for CHD every year.<sup>vi</sup>
- While most CHD hospital admissions are children, a growing percentage are adults.<sup>v</sup>
- 63% of adult CHD emergency department cases are admitted to the hospital.<sup>vii, viii</sup>
- Nearly 95% of patients of all ages hospitalized with CHD have some form of insurance at the time of discharge.<sup>vi</sup>
- Children with CHD who are hospitalized with a cardiac diagnosis have a 15% likelihood of being readmitted within a month of discharge.<sup>viii</sup>
- Individuals with CHD are significantly more likely to be discharged from the emergency department if they are uninsured or on Medicaid.<sup>vii</sup>
- Uninsured infants with CHD are 3 times more likely to die within the first month of life than are privately-insured infants.<sup>ix</sup>
- Infants with CHD from socio-economically disadvantaged areas have a 49% greater likelihood of mortality than infants from areas with higher socio-economic status.<sup>x</sup>
- Families of children and adults with CHDs can face additional costs, such as lifestyle changes, emotional stress, family uncertainty, and the inability to return to work in order to care for their family member.<sup>xi</sup>

### Opportunities to address CHD public health issues

- Surveillance and research to assess patterns of access to care and resource utilization across the lifespan
- Public health education and awareness for both providers and patients to reinforce the need to stay in care
- Access and coverage for specialty care such as cardiology, behavioral and mental health, nephrology, gastroenterology, and neurology.



<sup>i</sup> Moons, P., et al (2010) "Temporal trends in survival to adulthood among patients born with congenital heart disease from 1970 to 1992 in Belgium" *Circulation* 122(22):2264-2272.

<sup>ii</sup> Agarwal S, Sud K, Menon V. (2016) "Nationwide Hospitalization Trends in Adult Congenital Heart Disease Across 2003-2012." *J Am Heart Assoc* Jan 19; 5(1).

<sup>iii</sup> Agarwal S, Sud K, Khera S, Kolte D, Fonarow GC, Panza JA, Menon V. (2016) "Trends in the Burden of Adult Congenital Heart Disease in US Emergency Departments." *Clin Cardiol* 39(7):391-8.

<sup>iv</sup> Bhatt AB, Rajabali A, He W, Benavidez OJ (2015) "High resource use among adult congenital heart surgery admissions in adult hospitals: risk factors and association with death and comorbidities." *Congenital Heart Dis.* 10(1):13-20.

<sup>v</sup> Gilboa, S. M., et al. (2016). "Congenital Heart Defects in the United States: Estimating the Magnitude of the Affected Population in 2010." *Circulation* 134(2): 101-109.

<sup>vi</sup> HCUP National Inpatient Sample (NIS). Healthcare Cost and Utilization Project (HCUP). 2014. Agency for Healthcare Research and Quality, Rockville, MD. [www.hcup-us.ahrq.gov/nisoverview.jsp](http://www.hcup-us.ahrq.gov/nisoverview.jsp)

<sup>vii</sup> HCUP Nationwide Emergency Department Sample. Healthcare Cost and Utilization Project (HCUP). 2014. Agency for Healthcare Research and Quality, Rockville, MD. [www.hcup-us.ahrq.gov/nisoverview.jsp](http://www.hcup-us.ahrq.gov/nisoverview.jsp).

<sup>viii</sup> Mackie, A. S., et al. (2008). "Hospital readmissions in children with congenital heart disease: a population-based study." *Am Heart J* 155(3): 577-584.

<sup>ix</sup> Kucik, J. E., et al. (2014). "Role of health insurance on the survival of infants with congenital heart defects." *Am J Public Health* 104(9): e62-70

<sup>x</sup> Kucik, J. E., et al. (2014). "Community socioeconomic disadvantage and the survival of infants with congenital heart defects." *Am J Public Health* 104(11): e150-157.

<sup>xi</sup> Connor, J. A., et al. (2010). "The meaning of cost for families of children with congenital heart disease." *J Pediatr Health Care* 24(5): 318-325.