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Project Update Issue 6

About CH STRONG

Since 2016, the mission of CH STRONG—the Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG—has been to gather information to improve the lives of people with heart defects. We sincerely appreciate everyone who provided information for CH STRONG.

In this newsletter, we share our most recent results of three new CH STRONG publications on survival, regular cardiology care (care for the heart), and health insurance and access to health care among young adults with heart defects.

On the next two pages, you will find highlights from these recent publications.

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Inside This Issue

“Survival From Birth Until Young Adulthood Among Individuals With Congenital Heart Defects: CH STRONG” published in the *Journal of the American Heart Association*

“Cardiology Care and Loss to Follow-Up Among Adults With Congenital Heart Defects in CH STRONG” published in the *American Journal of Cardiology*

“Health Insurance Status and Access to Healthcare Among Young Adults with Congenital Heart Disease: from the Congenital Heart Survey To Recognize Outcomes, Needs and well-beinG (CH STRONG), 2016–2019” published in the *Journal of Pediatric Cardiology*

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Survival from Birth to Young Adulthood among People with Heart Defects

Congenital heart defects remain the leading cause of infant death associated with birth defects. However, with improvements in treatment, many people with heart defects are surviving and living longer.

Therefore, CH STRONG researchers examined the patterns in survival among people with heart defects and found that ...

8 in 10
survived to at least age 35.



After the first year of life,
over 9 in 10 survived to at
least age 35.



Overall, survival is good but may differ by

- Severity of the heart defect,
- Presence of other birth defects, and
- Low weight at birth.

Survival can also differ by race and ethnicity,
possibly due to differences in access to
quality care and prejudice.



Cardiology Care and Loss to Follow-Up among People with Heart Defects

Though treatments for heart defects have improved, many people with a heart defect are not cured, even if their heart defect has been repaired. People with a heart defect can develop other health problems over time.

Ongoing appropriate cardiology care for their heart defect will help people live as healthy a life as possible, but many young adults with heart defects do not receive the care they need.

CH STRONG researchers found that ...



Half of young adults with congenital heart defects had not received cardiology care (care for their heart) in the past 5 years.

The top reasons they had not seen a
cardiologist in 5 years ...



They felt well.



They did not think they needed to
see a heart doctor.

Even if you feel well now, it's a good idea to have regular check-ups with a cardiologist to prevent new heart problems or catch them before they become serious.

Health Insurance and Access to Health Care among Young Adults with Heart Defects

People with congenital heart defects require lifelong care for their heart which can be costly. Having health insurance may improve access to health care, including access to doctors with special knowledge of heart defects.

Therefore, CH STRONG researchers investigated health insurance coverage and healthcare access among young adults with heart defects and found that ...



1 in 10

Young adults with heart defects had no health insurance.

Compared with those with insurance, people with heart defects without insurance were ...



Less likely to see a doctor regularly. Only half of those without insurance had visited a doctor's office in the past year.



More likely to have had an emergency room visit in the last 12 months.



More likely to have depression.

Monitoring and treatment for a heart defect can be costly, even for adults with health insurance, but there may be help. Talk to your heart doctor and medical team for more information about and eligibility criteria for state-sponsored programs to help families meet their medical expenses.

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