



- Courtesy photo

## Local nonprofit advocates for a heart-safe community

Goal to provide auto defibrillator to every middle/high school in GJ

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FREE PRESS STAFF REPORT

**Name of agency: ARVDHeart for Hope, a Colorado nonprofit corporation**

Contact info:

ARVDHeart for Hope

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Hours of operation: 8 a.m.-5 p.m., Monday through Friday

Year founded: 2010

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What do you do and whom do you serve? The mission of ARVDHeart for Hope includes increasing awareness of ARVD heart disease, a source where individuals diagnosed with ARVD can obtain helpful, current information about this progressive heart disease, and promoting and raising funds for research.

ARVD stands for arrhythmogenic right ventricular dysplasia. Arrhythmogenic means “causing an arrhythmia” or an irregular heartbeat.

ARVD causes muscle cells in the lower right heart chamber to be replaced with fat and fibrous scar tissue. The fatty and fibrous tissue interfere with the flow of electrical signals, resulting in abnormal heart rhythms, rapid heartbeats, and sometimes sudden cardiac death.

Most patients with ARVD have both structural and electrical abnormalities. This condition affects men and women of all races. While ARVD is most commonly diagnosed in adults in their 20s and 30s, both children and older people have been diagnosed with this disease.

ARVD accounts for as many as 20% of sudden cardiac deaths in patients under 35 years of age. It's possible to have this disease without knowing it.

Board members: Sue Edson, president; Roy Billings, treasurer; Katherine Nielsen, secretary

Brief history: In November 2006, our daughter, Lindsey Beechwood Hoffner, 21 at the time, was diagnosed with ARVD after experiencing heart-related symptoms and undergoing a complex series of tests and evaluations.

A few weeks later, Lindsey received an implantable cardiac defibrillator (ICD) and medications to reduce her risk of sudden cardiac death and to correct her heart rhythms.

Proudest accomplishment: Our website, [www.arvdheart.org](http://www.arvdheart.org), went public May 2010. Since that time, we have raised over \$7,000 for research. Our website also provides a source where individuals diagnosed with ARVD can obtain helpful, current, and easy-to-read-and-understand information about this heart disease. We recently updated the site to include an ARVC Calculator (diagnostic link) for physicians to help determine if their patient meets the new Task Force Criteria for ARVD.

Signature fundraising events: In February 2010, our Heart Letter Fundraiser raised over \$6,500 for ARVD research.

How can the community get involved?: ARVD research is very under-funded. Ongoing, aggressive research is critical to improve the lives of those diagnosed with ARVD, and to provide medical breakthroughs and new treatment options for all ARVD patients and their families who suffer from this disease.

You can make a tax deductible donation for ARVD research by visiting [www.arvdheart.org](http://www.arvdheart.org). Thank you!

Future plans: Last year, 7,000 children under the age of 18 died from cardiac arrest, and only half of those had been diagnosed with a cardiovascular disorder. Youth are not routinely screened for heart conditions, and many schools aren't prepared for a cardiac emergency.

An AED, or automated external defibrillator, is a medical device designed to quickly analyze the heart's rhythm and safely deliver a shock, if needed.

Immediate response to cardiac arrest with an AED and CPR can make the difference between life and death to a victim.

Locally, School District 51 has no budget to start an AED program. I am pursuing action to have an AED readily available for every high school and middle school in Grand Junction to increase the survival rate for a victim of sudden cardiac arrest, whether it is a student, school athlete, parent, teacher or visitor.

In addition, since youth aren't routinely screened for heart conditions, ARVDHeart for Hope encourages parents of teens, especially those participating in sport activities, to ask their doctor for an ECG (a noninvasive test) and/or cardiac testing for their son or daughter.

ARVDHeart for Hope advocates heart screenings in youth for the early detection of risk factors and conditions associated with sudden cardiac arrest. Children's hearts change as they grow, so repeat evaluations are often needed.

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