



ARVC PATIENT ASSOCIATION  
for Germany, Austria and Switzerland

Our affair of the heart:  
Moving forward together

**A**rrhythmogenic  
**R**ight **V**entricular  
**C**ardiomyopathy

[www.arvc-selbsthilfe.org](http://www.arvc-selbsthilfe.org)

## What is ARVC?

ARVC (**a**rrhythmogenic **r**ight **v**entricular **c**ardiomyopathy) or ARVD (**d** for dysplasia) is an inherited rare disease of the heart muscle (cardiomyopathy) with fibrofatty replacement of heart muscle cells. These changes cause various dysfunctions of the heart: (1) False electrical signals may lead to palpitations, arrhythmias (abnormal heart rhythms) and syncope (loss of consciousness), and even to sudden cardiac death (SCD). (2) A reduced pumping action of the heart may lead to progressive heart failure.

Although described as a disease of the right ventricle, the left ventricle can be affected as well, leading to frequent misdiagnosis. The diagnosis of ARVC should be established according to the revised Task Force Criteria 2010, including changes in ECG, imaging techniques (e.g. cardiac ultrasound and MRI), family history (e.g. the SCD of a family member) and genetic testing. In 50-60%, a mutation in desmosomal proteins will be found. The carrier of a mutation will pass it to a child with a 50:50 chance. Risk stratification is not always easy, but can identify endangered persons. To prevent a possible SCD, the implantation of an ICD (implantable cardioverter-defibrillator) may be advisable. There is no cure for ARVC, but a medication with betablockers, sotalol and/or amiodarone helps to decrease arrhythmias and improve the pumping of the heart. Strenuous physical activity, especially competitive sports, should be avoided. Life-long follow-up is warranted for carriers without clinical symptoms although the disease may never break out during lifetime.

## What connects us?

The diagnosis ARVC can be a profound turning point in someone's life. Patients without symptoms can raise questions: Will the disease break out and if so, when? How can I decelerate or avoid the progress of the disease? For patients with symptoms, medical questions can arise: Which examinations and treatments are available and advisable? Are there any recent developments? At which point will the implantation of a defibrillator be necessary? Both groups begin to question the own physical capacity, lifestyle (From which physically exhausting and dangerous activities could I refrain?) and family planning.

In addition to that, medically non-affected family members fear for their relatives. The disease is often discovered first after the death of a close relative. Mourning for the deceased is therefore connected to the confrontation with a dangerous disease. The complexity of these issues is a challenge, not just for individuals but also for entire families whose members deal with their diagnosis sometimes in different ways. The exchange of experiences with other affected families can help patients to deal with the diagnosis.

# What are our goals?

## **Information**

Sharing knowledge, obtaining recent information about ARVC and asking questions in a protected environment, finding answers and developing a deeper understanding of one's own situation

## **Community and Closeness**

Contact and exchange with people having similar concerns, problems or experiences

## **Orientation and Opportunities**

Finding ways in difficult ARVC-related situations, managing crises with the help of the group, developing new strategies in dealing with ARVC and activating forces inside and outside the group

## **Solidarity and Encouragement**

Providing confidence and strength: We are not on our own because we are in touch with people having similar experiences and with doctors guaranteeing ideal treatment

## **Mission**

Improving the diagnosis of ARVC, encouraging the development of new therapies, intensifying research and preventing sudden cardiac death

# We are offering

- Experience and knowledge transfer (members are physicians or biologists)
- Exchange between numerous affected patients with different symptoms and therapies
- Access to information, therapies, and state of the art research on ARVC
- Group meetings, with exchange of information and experience
- Organization of lectures and talks about ARVC
- Support in acute crisis situations
- Availability in case of discussion and information needs
- Search for new medical knowledge about ARVC
- Participation in specialist lectures and congresses
- Regional and transregional networking with patients, physicians and research institutions
- Support for physicians and other patient advocacy groups to improve the diagnosis and treatment of ARVC patients
- Promotion of research projects
- Increased public awareness of the disease



ARVC-SELBSTHILFE E.V.

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## DONATION ACCOUNT

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Donations are tax-deductible and donation receipts can be issued on request

## MEMBERSHIP

We represent the interests of ARVC patients and relatives on European level in the ePAG (European patient advocacy group) of the European Reference Network (ERN) Guard-Heart



**European  
Patient  
Advocacy  
Group**

## THANKS TO

The Round Table of German Health Insurance Companies, which has sponsored our ARVC patient advocacy group since 2015