



Arrhythmogenic (Right Ventricular) CardioMyopathy (ACM)



- INFORMATION
- MEET-UPS
- ADVICE
- NETWORKING
- PATIENT ADVOCACY
- FUTURE PERSPECTIVES



Our Heartfelt Goal:

Moving Forward Together



www.arvc-selbsthilfe.org

What is ARVC?

ARVC, or more generally ACM, is a primarily hereditary heart disease in which heart muscle cells are replaced with fat and/or connective tissue.

This replacement process can lead to cardiac arrhythmias, and more rarely, to heart failure or even sudden cardiac death.

POSSIBLE SYMPTOMS

- Palpitations, skipping or racing heartbeat
- Dizziness or fainting
- Pressure or pain in the chest
- Shortness of breath, breathlessness
- Fatigue or exhaustion

DIAGNOSIS

The presence of disease may be indicated by ECG, echocardiogram, or MRI results, or if there is a family history of sudden cardiac arrest or death. Genetic testing may help to confirm the diagnosis and identify at-risk relatives.

Not every carrier of a genetic variant will develop clinical symptoms within his or her lifetime. There are overlaps with DCM (dilated cardiomyopathy) in left dominant or biventricular forms.

TREATMENT

The symptoms of ARVC can be treated with medication and/or with a catheter ablation procedure. To reduce the risk of sudden cardiac death, an implanted defibrillator is recommended for patients with high-risk profiles.



"Receiving the diagnosis of ARVC can have an enormous impact on one's life. We're committed to ensure that those affected receive comprehensive care, and we provide resources that support them throughout their challenging journey."

Ruth Biller, Chairperson ARVC-Selbsthilfe e.V.

IN SHORT:

ACM, AVC, AC

Umbrella term for all types, including biventricular

ARVC, ARVD

Typical right-dominant presentation

ALVC, NDLVC

Left-dominant variants



A = Arrhythmogenic
Arrhythmia-causing

ND = non-dilated
not expanded/enlarged

V = ventricular
Ventricle-affecting

C(M) = Cardiomyopathy
Disease of the heart muscle

D = Dysplasia
Malformation (outdated term)

R = right

L = left

We're here for you!



LOCAL CONTACT PARTNERS

Across Germany, members of our group are available for conversation and communication. In some regions, there are also in-person meet-ups.

For the most up-to-date contact information, please visit our website.

ARVC-HOTLINE & E-MAIL

For questions about the disease, the organisation and counselling after sudden cardiac death

+49 163-18 47 521 or
info@arvc-selbsthilfe.org



Homepage



SCAN ME

On our website, you can find the most up-to-date event schedule, more information about ARVC, and opportunities to get on our mailing list or become a member of our association.

www.arvc-selbsthilfe.org

ARVC-Selbsthilfe e.V.

c/o Ruth Biller • Fastlingerring 113 • D-85716 Unterschleißheim

Our Network:



Allianz Chronischer Seltener Erkrankungen



European Patient Advocacy Group



European Reference Network
for rare or low prevalence complex Heart Diseases (ERN GUARD-HEART)



Bundesverband Herzkrank Kinder e.V.



SUPPORTING MARVEL. SAVING LIVES.



EURORDIS
RARE DISEASES EUROPE



Global Heart Hub

INFORMATION

CLEAR & UP TO DATE

Have you just recently received the diagnosis and do you have a lot of questions? Or have you been living with this disease for a while, but still want to understand some things more precisely?

We'll help you find the answers you're looking for.



Jutta Wevers,
ARVC patient

"The conversations really helped me to come to terms with this diagnosis, which so suddenly affected almost all my family members and to understand what the risks were for us. There is a sympathetic ear for all questions."

• LECTURES - LIVE & ONLINE

Concentrated knowledge on chosen themes regarding ARVC/ACM

• Q&A-SESSIONS

Patients ask - experts answer

• HOMEPAGE

Extensive information on living with the disease

www.arvc-selbsthilfe.org

• YOUTUBE CHANNEL

Our videos are here:
[ARVC-Selbsthilfe e.V.](https://www.youtube.com/channel/UC...)



SCAN ME

• ARVC SYMPOSIUM

ARVC-Selbsthilfe Meet-up with experts



MEET-UPS

REGIONAL & CROSS-REGIONAL



Do you wish to have contact with others affected by ARVC? Do you want to share some of your own experiences and learn how others are coping?

Together, we can find our way out of crisis and develop new strategies for managing this disease.

• WEEKEND MEET-UPS

A weekend in Germany with the whole "ARVC Family". A great opportunity to meet new people, catch up, get useful tips and gain insight into the life of others.

• REGIONAL MEET-UPS

Meet-ups with others affected by ARVC from your area, organised by our local partners in Germany.

• ONLINE MEET-UPS

Meet other ARVC patients without travelling, from the comfort of your own home.

• PATIENT FORUM

Ask questions, discuss personal topics, and share stories. A moderated online community is available on www.arvc-selbsthilfe.org/forum/ *

*German language



SCAN ME



Vero Lüscher,
ARVC patient

"The day-to-day living with ARVC was very hard for me in the beginning. Am I allowed to exercise; what is it like to live with a defibrillator; what else do I have to worry about...? Connecting with others affected by ARVC is very helpful with all of that."

FUTURE PERSPECTIVES

SCIENCE & RESEARCH

ARVC is a rare disease, for which there is still a great need for research. We support research on basic knowledge of the disease mechanisms, the faster achievement of a diagnosis and the development of future treatment strategies.



• SCIENTIFIC ADVISORY BOARD

Close cooperation with ARVC experts from practices, hospitals and research

• STUDIES, PATIENT REGISTRIES AND BIOBANKS

Financial and organisational support for various projects

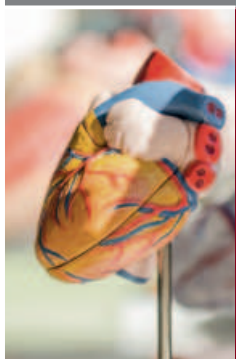
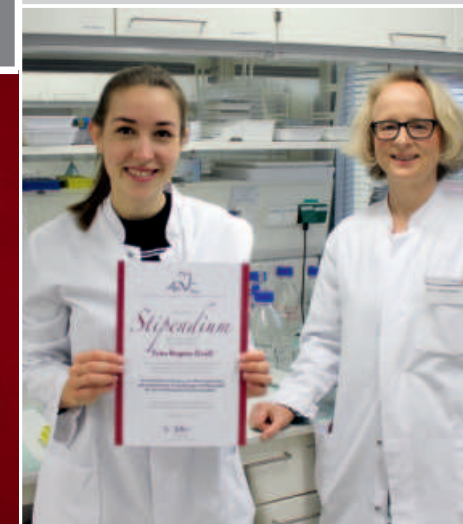
• TRAINING & EDUCATION

Participation in (inter-)national conferences, literature review of state-of-the-art medicine and recent study results



Prof. Dr. med.
Eric Schulze-Bahr,
Member of the Scientific
Advisory Board

"The ARVC-Selbsthilfe provides outstanding help with everything that is important: a personal, psychological and medical understanding of and information about your disease."



ALSO FIND
US ON:



Our Heartfelt
Goal:
**Moving
Forward
Together**

