

Annual ARVC Patient and Family Seminar

*Presented by
The Johns Hopkins ARVC Program*

You and your family members are invited to join us for our annual Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC) Seminar! This year the seminar will once again be held in-person, but it will also be livestreamed for those unable to join us in Baltimore. We will be utilizing the WHOVA platform where you will also have the opportunity to correspond with other attendees via chat groups. We hope you will consider joining in person to take full advantage of the opportunity to meet other individuals and families, participate in research opportunities, and interact with industry, specifically gene therapy companies.

We are thrilled to have two invited guest speakers, Sam Sears, PhD, cardiac psychologist, and Dominic Abrams, MD, MRCP, adult and pediatric electrophysiologist specializing in inherited cardiac conditions, including ARVC. In addition, we will have presentations from our own Johns Hopkins faculty; Andreas Barth, MD, PhD; Nisha Gilotra, MD; Konstantinos Aronis, MD, PhD; Cindy James, PhD; and Brittney Murray, MS, CGC. You won't want to miss this unique opportunity to meet and network with other families affected by ARVD/C and to learn the latest advances in the field. It will be exciting to share the collaborative efforts all around the world in solving the mysteries of ARVD/C.

Make plans to come into Baltimore early to attend a reception at the Hilton Garden Inn Friday evening (7pm-9pm). Heavy hors d'oeuvres will be served. This event is for patients and family members only. No industry representatives please.

Please register early! There is no registration fee for this seminar, but we continue to be mindful of our gathering capacity. You must register to attend (in-person and virtual).

WHEN: Saturday, April 5th, 2024 8:00am-5:00pm

COST: Registration is **FREE**. You just need to get here!

WHO: Patients and Families affected by ARVD/C, Healthcare Professionals

WHERE: Chevy Chase Conference Center Auditorium
Main level of Sheikh Zayed Tower
1800 Orleans Street
Baltimore, Maryland 21287

REGISTRATION: ALL participants must register! It is also helpful to list names of family members that will be attending with you so we can determine appropriate research opportunities. Register online by March 29th.

<https://tinyurl.com/ARVC2025>

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HOTEL ACCOMMODATIONS – RESERVE EARLY!!!

Hotel rooms are available (limited) at the Homewood Suites Baltimore Inner Harbor (625 South President Street, Baltimore, Maryland 21202) at a special rate of \$171/night plus tax until March 14th, 2025 or as long as they are available.

Hotel reservations can be made through the Hilton Garden Inn Central Reservations Line at **888-429-7482**. The group name is **ARVC Program Seminar Group** and the reservation link name is **ARVC Program Seminar Group**. Reservations can also be made through the online booking link:

<https://group.homewood-suites.com/ksbv6>

The hotel front desk can be reached at 410-234-0999. Check-in 3pm / Check-out 11am. Self-Parking is available at a rate of \$25 per day.

TRAVEL TIPS

The Baltimore/Washington International (BWI) Thurgood Marshall Airport is the closest international airport to Johns Hopkins (www.bwiairport.com). It is approximately 30 minutes from the seminar location.

Transportation from Hotel to Seminar – Uber and Lyft are recommended and is at your own expense. There is **no** bus transportation to and from the seminar.

PARKING AT THE SEMINAR

Parking is available at your own expense (max \$15) in the Orleans Street Garage. There is a bridge that connects the garage to the main level of Sheikh Zayed Tower (4th floor).

SPECIAL EVENT

Join us for a Meet 'n Greet Reception, **7:00-9:00pm**, on **Friday, April 4th, 2025** in the Garden Grille and Bar at the Homewood Suites/Hilton Garden Inn. Please register for this event when you register for the seminar or contact Crystal. Patients and family members only. No industry representatives please.

CLINIC CONSULTATIONS – REQUEST YOUR APPOINTMENT NOW!!!

Dr. Hugh Calkins and the genetic counselors will be available Friday, April 4th and Monday, April 7th for consultations. Dr. Nisha Gilotra will also have a few clinic slots available. Diagnostic tests can also be arranged if necessary. We ask that if you live locally to please consider arranging your appointment at another time to allow new patients and patients traveling from a distance an opportunity to schedule. These appointments will be billed to your insurance. Please contact Crystal via email at ctichnell@jhmi.edu **ASAP** to schedule an appointment.

Share Your Story

Looking for patient/family stories to share! If you are interested in sharing your story for others to read, please make sure your story and any photos you'd like to include can fit on an 8x10 page. Stories need to be submitted to Crystal by March 21st.

COVID-19

Masking is optional. We encourage self-testing prior to attending.

QUESTIONS

Contact Crystal Tichnell, MGC, RN at 410-502-7161 or ctichnell@jhmi.edu