

JOHNS HOPKINS ARRHYTHMOGENIC RIGHT VENTRICULAR DYSPLASIA/CARDIOMYOPATHY PROGRAM

Volume 12, Issue 1

Winter 2022

* ** ***!!!HAPPY HOLIDAYS!!!*** ** *

Happy Holidays from the Johns Hopkins ARVC team! We wish you all good health, happiness, and success in the coming year and always! We are so excited to offer our patient and family seminar **IN-PERSON** in 2023! We look forward to seeing all who plan to make the trip to Baltimore. You will find additional details later on in this newsletter. We've had another busy year and look forward to sharing some new information with you.

Many of you might be aware of Dr. Hari Tandri's recent departure from Johns Hopkins to accept a position at Vanderbilt as Chief of Electrophysiology. We are excited for him to take this opportunity but miss him already! Please rest assured that our team will continue to provide all of your ARVC clinical care needs. We also continue to collaborate with Dr. Tandri on various research initiatives. We are excited for Dr. Jonathan Chrispin to join the team and taking over any complex ablation procedure needs.

Our program is busier than ever collaborating with centers around the world to unravel the mysteries of ARVC. Gene therapy is on the horizon and we are excited to collaborate with several companies looking at gene therapy for PKP2 type ARVC. Still lots of work to be done, but an incredible opportunity nonetheless. We encourage you to enroll in our ARVC Registry as this will be our recruitment source for upcoming studies.

~ The ARVD/C Program

Hugh Calkins, Cindy James, Brittney Murray, and Crystal Tichnell

Annual ARVD/C Patient and Family Seminar

*Presented by
The Johns Hopkins ARVD/C Program*

You and your family members are invited to join us for our annual ARVD/C Seminar! This will be our first in-person conference since the COVID-19 pandemic and we are thrilled! We are honored to have two invited guest speakers, Sam Sears, PhD from East Carolina University and Mario Delmar, MD from NYU Langone Health. In addition, we will have presentations from our own Johns Hopkins faculty; Andreas Barth, MD, PhD; Nisha Gilotra, MD; Jonathan Chrispin, MD; Cindy James, PhD; Brittney Murray, MS. 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. We are eager 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.

Registration is required so please register early! There is no registration fee for this seminar, but we continue to be mindful of our gathering capacity limits. If you need to cancel, please let us know ASAP, so we can plan accordingly.

WHEN: Saturday, April 22nd, 2023 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



Mario Delmar, MD



Sam Sears, PhD

REGISTRATION: ALL participants must register. Please also list names of family members that will be attending with you so we can determine appropriate research opportunities. **Register online by April 8th.**

NOTE: Masking is required in all Johns Hopkins facilities.

<https://tinyurl.com/2023ARVCSeminar>

23rd Annual ARVD/C Patient and Family Seminar

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The Johns Hopkins ARVD/C Program*

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HOTEL ACCOMMODATIONS – RESERVE EARLY!!!

Hotel rooms are available (limited) at the Homewood Suites by Hilton, Baltimore Inner Harbor (625 South President Street, Baltimore, Maryland 21202) at a special rate of \$179/night plus tax until March 21st, 2023 or as long as they are available.

Hotel reservations can be made through the Homewood Suites Central Reservations Line at **888-429-7481**. The group name is **Johns Hopkins ARVD/C** and the group code is **ARV**. Reservations can also be made through the online booking link: <https://www.hilton.com/en/attend-my-event/johns-hopkins-arvdc-hw/>

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 and valet \$35 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. Transportation to and from the seminar is at your expense and coordination – we will not provide bus transportation this year.

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 21st, 2023** in the Great American Grill at the Homewood Suites/Hilton Garden Inn. Please register for this event when you register for the seminar or contact Crystal.

CLINIC CONSULTATIONS – REQUEST YOUR APPOINTMENT NOW!!!

Dr. Hugh Calkins and the genetic counselors will be available Friday, April 21st and Monday, April 24th 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 April 10th.

COVID-19

Masking is required in all Johns Hopkins facilities. We encourage masking when not consuming food/beverages at the Meet 'n Greet. We encourage self-testing prior to attending.

QUESTIONS

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

Effects of Flecainide on Cardiac Arrhythmias in ARVC Patients

Johns Hopkins IRB00197430

Funded by The National Institutes of Health (NIH)

Principal Investigator: Hugh Calkins, MD

Enrolling Site Coordinator: Crystal Tichnell, MGC, RN

The purpose of this study was to assess the effect of the antiarrhythmic drug, flecainide, on cardiac arrhythmias in individuals with ARVC utilizing a randomized, double-blinded, crossover study format. Enrollment for this trial has ended, with Johns Hopkins enrolling the most patients. Thank you those who participated in this trial! We expect to have results to share in our next newsletter.

Identification of mechanism-based therapies to treat arrhythmogenic cardiomyopathy by resolving perturbations in regulatory lipid signaling

Johns Hopkins IRB00321262

This study is being done in collaboration with the company EicOsis and involves collection of blood samples to characterize inflammation in Arrhythmogenic Cardiomyopathy (ACM) patients and compare it to non-affected family member matched controls. In addition, we will be combining de-identified clinical, genetic, and family history data with the inflammatory marker data EicOsis gets from your blood samples to understand whether these inflammatory markers are abnormal in ACM patients and family members. You must be enrolled in the "Clinical and Genetic Investigations of Right Ventricular Dysplasia", NA_00041248 (aka the Johns Hopkins ARVC Registry) and will be invited to participate at your clinical appointment or seminar should you meet eligibility criteria. This information will help pave the way for future clinical medication trials.

RESEQUENCE-GC Randomized clinical trial of the sequence of genetic counseling and testing to optimize efficiency, patient empowerment and engagement, and medical adherence for diverse cardiovascular genetic testing indications, or RESEQUENCE-GC

Principal Investigator : Dr. Cindy James, PhD, CGC

Study ID: IRB00320656

ClinicalTrials.gov Identifier : NCT05422573

The RESEQUENCE-GC study is an NIH funded study to explore different models of providing genetic counseling and comparing their effectiveness to the standard of care model. Standard of care for the structure of the genetic counseling process is generally a more in-depth pre-genetic-testing consultation with a genetic counselor, followed by a typically much shorter results disclosure conversation upon completion of genetic testing. As genetic testing continues to become more widely accessible and more consistently recommended, it is possible that other models of genetic counseling services may be equally as effective as the standard of care model while improving efficiency.

Individuals who are scheduling at Johns Hopkins for a first time appointment with a cardiac genetic counselor are eligible for this study. A team member will let you know if you are eligible for this study at the time of scheduling.

Research Opportunities at Johns Hopkins

Why Participate in a Clinical Trial?

Clinical trials are so important in discovering new treatments and the safety of those treatments, particularly of rare conditions. The decision to participate in a clinical trial is a personal one and only you can decide if it's the right choice for you. As you think about whether to participate, please take a minute to consider the impact your participation or non-participation might have on overall clinical trials in ARVC. As we all know, ARVC is a rare condition and there isn't much funding for research, so we need to make the most of it. We need to prove to big funding agencies that individuals with ARVC are interested and willing to participate in new discovery research, otherwise, there will be huge delays in new discoveries, new treatment options, and ultimately finding a cure. To be considered for any ARVC related clinical trials enrolling at Johns Hopkins, you will need to be enrolled in the ARVD/C Registry (Clinical and Genetic Investigations of Right Ventricular Dysplasia) discussed below.

<https://www.nih.gov/health-information/nih-clinical-research-trials-you/basics>

Clinical and Genetic Investigations of Right Ventricular Dysplasia (ARVD/C Registry)

This registry is the heart of our program and from which all of our research projects originate. Both children and adults either diagnosed with ARVC or a family member of someone diagnosed with ARVC are eligible to participate. Participation involves submission of past medical records and continued followup for at least 5 years. A DNA sample may be collected for specific projects. Reach out to Crystal at 410.502.7161 or ctichnell@jhmi.edu to join.

Featured Manuscript

Subcutaneous and Transvenous Defibrillators in Arrhythmogenic Right Ventricular Cardiomyopathy: A Comparison of Clinical and Quality-of-Life Outcomes.

Weijia Wang, Alessio Gasperetti, Samuel F Sears, Crystal Tichnell, Brittney Murray, Harikrishna Tandri, Cynthia A James, Hugh Calkins. *JACC Clin Electrophysiol.* 2022 Oct 21;S2405-500X(22)00846-5. doi: 10.1016/j.jacep.2022.09.020.

Objective: This study aimed to compare clinical and quality-of-life outcomes between transvenous and subcutaneous ICDs among patients with ARVC. **Methods:** Patients with a subcutaneous ICD (n=57) were matched to patients with a transvenous ICD (n=88) based on sex, proband status, primary prevention or secondary prevention, monomorphic ventricular tachycardia before implantation, and year of implantation. Appropriate therapy for ventricular arrhythmia, inappropriate shocks, and complications were compared. Quality-of-life surveys were conducted annually. **Results:** No significant difference was observed in the rate of appropriate ICD shocks. The subcutaneous group had more inappropriate shocks (23% vs 10%) and fewer procedure-related complications (4% vs 14%) than the transvenous group. A subcutaneous ICD was associated with more body image concerns and range of motion than a transvenous ICD. **Conclusions:** In patients with ARVC receiving an ICD, the risk of inappropriate shocks from a subcutaneous ICD should be balanced against the significant vascular complication risk from a transvenous ICD. Patients with a subcutaneous ICD had more concerns for body image and range of motion.

2022 Publications

- Malik N, Mukherjee M, Wu KC, Zimmerman SL, Zhan J, Calkins H, James CA, Gilotra NA, Sheikh FH, Tandri H, Kutty S, Hays AG. **Multimodality Imaging in Arrhythmogenic Right Ventricular Cardiomyopathy.** *Circ Cardiovasc Imaging.* 2022 Feb;15(2):e013725. doi: 10.1161/CIRCIMAGING.121.013725. Epub 2022 Feb 11. PMID: 35147040 Review.
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- Giuliano K, Scheel P 3rd, Etcill E, Fraser CD 3rd, Suarez-Pierre A, Hsu S, Wittstein IS, Kasper EK, Florido R, Tandri H, Calkins H, Choi CW, Sharma K, Kilic A, Gilotra NA. **Heart transplantation outcomes in arrhythmogenic right ventricular cardiomyopathy: a contemporary national analysis.** *ESC Heart Fail.* 2022 Apr;9(2):988-997. doi: 10.1002/ehf2.13687. Epub 2022 Feb 8. PMID: 35132806 Free PMC article.
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- Sharma A, Bosman LP, Tichnell C, Nanavati J, Murray B, Nonyane BAS, Tandri H, Calkins H, James CA. **Arrhythmogenic Right Ventricular Cardiomyopathy Prevalence and Arrhythmic Outcomes in At-Risk Family Members: A Systematic Review and Meta-Analysis.** *Circ Genom Precis Med.* 2022 Jun;15(3):e003530. doi: 10.1161/CIRCGEN.121.003530. Epub 2022 May 17. PMID: 35579515
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Sudden Cardiac Arrest (SCA) Awareness: Courtney's Story by Anna Goodson

Johns Hopkins Heart & Vascular Institute sincerely thanks the SADS Foundation for their collaboration on this patient story. Visit SADS.org for more information.

Courtney West didn't know that she had a potentially fatal heart condition until her brother, Jacob, died suddenly during a football practice from sudden cardiac arrest (SCA) in 2013.

Jacob was a multisport athlete who'd had several school physicals, none of which showed any problems. "We were completely blindsided," says Courtney.



After Jacob's death, doctors suspected it was due to a genetic heart condition. Courtney began an extensive testing process. She had multiple arrhythmias (abnormal heart rhythms) during a stress test, which led to a diagnosis of ARVC (arrhythmogenic right ventricular cardiomyopathy), a progressive genetic disease of the heart muscle.

Courtney has received care from Johns Hopkins Medicine, which has one of the top programs in the United States for treatment and management of this rare heart condition.

"My first visit at The Johns Hopkins Hospital was life changing, because I hadn't had an experience before where I walked into a medical space and everyone understood exactly what I was going through," says Courtney. "It made me hopeful for the first time since being diagnosed."

Among the practitioners Courtney sees are Harikrishna Tandri, M.B.B.S., Hugh Calkins, M.D., Brittney Murray, M.S., and Crystal Tichnell, M.G.C. This incredible team works closely with the SADS (Sudden Arrhythmia Death Syndrome) Foundation, a patient advocacy nonprofit organization. Its mission is to save the lives and support the families of children and adults who are genetically predisposed to sudden death due to heart rhythm abnormalities such as ARVC.

"The SADS Foundation support makes you feel like you are important and seen," says Courtney. "They make you feel like you're not alone."

Courtney and her family are spreading awareness about SCA and what bystanders can do to save a life when a cardiac emergency occurs, including knowing where the closest AED (automated external defibrillator) is, making sure its batteries are charged and knowing how to use it.

"When my brother had his SCA, there was no AED on the field," Courtney says. "And that could have saved his life. My family lives with that knowledge every day — that Jacob might be here today, a happy 26-year-old, if only an AED had been on the field. There is no wrong place for an AED."

She wants others with conditions like ARVC to know that the most important thing is connecting with experts such as those on the Johns Hopkins ARVC team.

"Knowledge is power with ARVC, and having that knowledge alleviates stress," she says. "Having a team who can help on your journey can bring you that power."

Clinical Services

The Johns Hopkins ARVD/C Program provides a variety of clinical services. We see patients for second opinion consultations to discuss diagnosis and management, genetic counseling and testing, routine ICD management and family member screening. We can also arrange concurrent cardiac testing.

New patients are seen in consultation with Dr. Hugh Calkins and our clinical genetic counselor, Brittney Murray, to discuss test results, family history, and to provide guidance regarding further management. We see all of our patients for genetic counseling to discuss the diagnosis, the psychosocial impact of living with ARVD/C and with an ICD, as well as to discuss the benefits and limitations of appropriate genetic testing. In selected cases, we also offer catheter ablation as a treatment for difficult to manage ventricular tachycardia. Appointments with our heart failure specialist, Dr. Nisha Gilotra, can also be arranged. All appointments are billed to your health insurance.

With the COVID-19 pandemic becoming less of an impact, licensure waivers are coming to an end. This means we are no longer able to offer telemedicine appointments with our physicians. However, there may be some flexibility with our genetic counseling ONLY visits to be able to continue to offer this option. Please reach out to Crystal to see if you are eligible for a telemedicine appointment based on your appointment needs and physical location. Remember, even if your condition is stable, you should be checking in at least once every two years with repeat cardiac evaluations. It is best to respond to early changes in your health, rather than react to an urgent situation.

To schedule an appointment, contact Crystal at ctichnell@jhmi.edu or 410-502-7161.



Meet Dr. Jonathan Chrispin

Jonathan Chrispin, M.D. is an Assistant Professor of Medicine in the Johns Hopkins Medicine Division of Cardiology, Electrophysiology and Arrhythmia. Dr. Chrispin focuses on all aspects of clinical electrophysiology, including pacemaker/defibrillator implantation, complex catheter ablation for atrial and ventricular arrhythmias and laser-lead extraction.

Dr. Chrispin received his bachelor of arts degree at Harvard College. He received his doctor of medicine degree from Vanderbilt University. He completed intern and residency training in internal medicine at The Johns Hopkins Hospital, where he also completed a fellowship in cardiovascular disease and served as chief clinical cardiac electrophysiology fellow. Dr. Chrispin is board-certified in internal medicine, cardiovascular disease and clinical electrophysiology.



Dr. Chrispin directs the Ventricular Arrhythmia research program with a focus on using advanced cardiac imaging to better understand the structural substrate that is associated with the development of ventricular arrhythmias. Further, he is involved in developing clinical trials to improve the safety and efficacy of catheter ablation for the treatment of ventricular tachycardia.

What is your favorite quote? *Everyone blossoms in their own time in different ways. Don't judge yourself by someone else's path- Oubaitori (Japanese Idiom)*

What inspires you? *My parents. They came to the US from Haiti with very little and showed me what hard work and determination could accomplish.*

What is your favorite activity when you're not in the EP lab? *I love road cycling! Though I recently picked up tennis which is fun and frustrating at the same time.*

What is one interesting fact about yourself? *I come from a very large family. I have 16 aunts/uncles and 31 first cousins*

How You Can Help

The Johns Hopkins ARVC/D Program provides world-class medical care. But **did you know** that the program relies heavily on outside donations to make a difference to ensure we are able to provide exceptional personalized care and to find more efficient and effective means to diagnose and treat our patients?



Did you know...FACT or MYTH?

- We need money from philanthropy to support staff, research, patient care and education.***
FACT!- We do! 75% of ARVC Program staff are financially supported by private funding/philanthropy.
- The pandemic did not affect our program.***
MYTH!- We continued consults throughout the pandemic thanks to telemedicine. Hospital wide, however, resources were diverted to caring for COVID-19 patients and elective procedures were significantly reduced. This overall reduced volume led to decreased revenues across the hospital and therefore reduced resources available to support the program.
- It is “easy” to acquire grants/funding for ARVC research.***
MYTH!- It is *much* more difficult to acquire outside funding through federal and private grants since ARVC is a rare disease. The Johns Hopkins Heart and Vascular Institute has the top ARVD/C Program in the country, under the leadership of Dr. Hugh Calkins. Patients and their families come to Johns Hopkins to receive an accurate diagnosis, treatment, genetic counseling, and family screening. We need **YOUR HELP** to continue this transformative work.
- An ARVC diagnosis has a huge impact on overall mental health of patients and their families.***
FACT!- We have plans to hire a mental health professional on our team to provide the support and resources that are so needed for this unique patient community. Studies have shown that patients with ARVC are at an elevated risk for anxiety. At least 30% of our patients have significant clinical anxiety and 10% are diagnosed with depression. We feel these numbers are underreported. This is long overdue and we need to do something NOW to support these mental health concerns.
- We rely heavily on contributions from grateful patients, families and friends to help us seek new information, improve treatments, and ultimately, A CURE!***
FACT! Your gift truly makes a difference.
- There are a variety of ways to donate and to support the program.***
FACT!
 - You can make an outright gift of cash or securities
 - Give in honor or in memory of a loved one
 - Give through IRAs, wills and trusts
 - Become a monthly donor
 - Be part of our online “Friend Raising” campaign. More info to follow!

To make a donation go to: <https://secure.jhu.edu/form/heart> (Select “**ARVD Research**” from the drop-down menu)

Or mail in donation to:

Johns Hopkins University and Medicine
Attn: Heart and Vascular Institute
PO Box 49143
Baltimore MD 21297-9143

(Be sure to include “ARVD Program” in the memo line of your check)

The Johns Hopkins Heart and Vascular Institute Development Office is here to help! Please contact Megan Lally, Associate Director of Development, at mlally2@jh.edu or 443-687-2947 for more information



Support Resources

Looking for support resources?

FACEBOOK Groups (private):

- ARVD/C Youth Society
- Hope for ARVD

PLN Heart Disease Foundation:

<https://www.plnheartdiseasefoundation.org>

Information for those of you affected by PLN or phospholamban type ARVC.

Precision Medicine Website:

Read "Feeling the Beat": Stories from the ARVC Community here:

<http://www.hopkinsmedicine.org/inhealth/precision-medicine-centers/arvc>

Sudden Arrhythmia Death Syndromes Foundation (SADS):

www.sads.org

An advocacy group for patients and families affected by a sudden arrhythmia death syndromes, including ARVC.



ARVD/C Program Info

ARVC Program Staff

Hugh Calkins, MD—Director
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Stefan Zimmerman, MD—MR Imaging
Allison Hays, MD—Echo Imaging
Cynthia James, ScM, PhD—Genetic Counselor
Brittney Murray, MS—Genetic Counselor
Crystal Tichnell, MGC, RN—Genetic Counselor, Nurse
Emily Graham—Genetic Counselor Assistant
Christal Holmes-Igwebike—Clinic Coordinator
Catherine Pendleton—Research Program Coordinator
Zeba Shaik—Research Program Coordinator
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Alessio Gasperetti—Research Fellow

Keep us informed of your most up-to-date contact info! Please send any changes and updated medical records to Crystal via the contact info below. Thank you!

Contact Us

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