

# JOHNS HOPKINS ARRHYTHMOGENIC RIGHT VENTRICULAR DYSPLASIA/CARDIOMYOPATHY PROGRAM

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\* \*\* \*\*\*!!!!HAPPY NEW YEAR!!!!\*\*\* \*\* \*

Are you ready to take on 2018??? From all of us here at the ARVD/C Program, we hope you and your families have a wonderful Holiday Season. We wish you good health, happiness, and success in the coming year and always!

Please know that your continued support both financially as well as through your research participation does not go unnoticed. Thank you for volunteering your records, your time, and your ideas. Advances that have been made in the field of ARVD/C are all because of your dedication. We truly value this partnership and look forward to improving our understanding of ARVD/C together. We cannot thank you enough!

We are excited to announce our Annual Patient and Family Seminar this Spring and hope to see many of you there. Details are enclosed. Please do not hesitate to contact our program with any questions or concerns.

~ The ARVD/C Program

## 19<sup>th</sup> Annual ARVD/C Patient and Family Seminar

You and your family members are invited to join us for our annual ARVD/C Seminar! You won't want to miss this unique opportunity to meet other families affected by ARVD/C and to learn the latest advances in the field. We are finalizing our agenda and will get that info out soon!

Continental breakfast and lunch will be served. There will be an opportunity to participate in a Q & A session, as well as opportunities to participate in research during the afternoon.

Make plans to come into Baltimore early to attend a reception at the Hilton Garden Inn Friday evening (7pm-9pm). We look forward to seeing many of you in May! Please register early! There is no registration fee for this seminar. All are welcome!

**WHEN:** Saturday, May 5<sup>th</sup>, 2018 8:00am-5:00pm

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

**WHERE:** PreClinical Teaching Building  
725 North Wolfe 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 April 15<sup>th</sup>.**

**<https://tinyurl.com/2018ARVCSeminar>**

Would you like to schedule a consultation with the ARVD/C Team while you are here for the seminar weekend?  
→ Then request your appointment **NOW!** ←

**Thursday, May 3<sup>rd</sup> (Dr. Tandri)**

**Friday, May 4<sup>th</sup> (Dr. Calkins)**

**Monday, May 7<sup>th</sup> (Dr. Calkins)**

These appointments go quickly! Your insurance company will be billed for these services. All new patients are scheduled with both Brittney and one of the physicians.

Contact Crystal @ 410-502-7161 or [ctichnell@jhmi.edu](mailto:ctichnell@jhmi.edu) to request an appointment.

# 19<sup>th</sup> Annual ARVD/C Patient and Family Seminar

*Presented by  
The Johns Hopkins ARVD/C Program*

## **HOTEL ACCOMODATIONS – RESERVE EARLY!!!**

Hotel rooms are available (limited) at the Hilton Garden Inn, Baltimore Inner Harbor (625 South President Street, Baltimore, Maryland 21202) at a special rate of \$172/night plus tax (single/double) until April 2<sup>nd</sup>, 2018 or as long as they are available.

Hotel reservations can be made through the Hilton Garden Inn Central Reservations Line at **1-888-429-7482**. Request **Johns Hopkins ARVD 2018 Group rate.**

The hotel front desk can be reached at 410-234-0065. Check-in 3pm / Check-out 12pm. Self-Parking is available at a rate of \$23 and valet \$32 per day.

## **TRAVEL TIPS**

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

Two buses will be available to transport seminar participants from the Hilton Garden Inn to the seminar on Saturday morning. Departure times TBD. The bus will leave the seminar at 5:00pm to return to the Hilton Garden Inn.

Taxi Services – For Taxi services call Sun Cab at 410-235-0300 or Yellow Cab at 410-752-1096. Uber and Lyft are plentiful in Baltimore as well.

## **PARKING AT THE SEMINAR**

If you are not taking the bus from the hotel, FREE parking (Saturday from 7am to 7pm) is available at the Washington Street Garage (701 Washington Street, Baltimore, MD 21205), just one block from the seminar location.

## **SPECIAL EVENT**

Join us for a Meet ‘n Greet Reception, **7:00-9:00pm**, on **Friday, May 4<sup>th</sup>, 2018** in the Great American Grill at the Hilton Garden Inn. Hors d’oeuvres will be served. Please register for this event when you register for the seminar or contact Crystal.

## **CLINIC CONSULTATIONS**

Dr. Hugh Calkins and Dr. Hari Tandri and the genetic counselors will be available Thursday, May 3<sup>rd</sup>, Friday, May 4<sup>th</sup> and Monday, May 7<sup>th</sup> for consultations. Diagnostic tests can also be arranged if necessary. These appointments will be billed to your insurance. Please contact Crystal **ASAP** to schedule an appointment.

## **RESEARCH**

Research opportunities will be available on Saturday afternoon and will include blood drawing, ICD interrogations, etc. **We must have your medical records ahead of time** to determine if you are eligible for research. You will not be able to participate if we do not have your records.

## **QUESTIONS**

Contact Crystal Tichnell, MGC at 410-502-7161 or [ctichnell@jhmi.edu](mailto:ctichnell@jhmi.edu)

## Clinical Services at Johns Hopkins

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.

Patients are seen in consultation with Dr. Hugh Calkins or Dr. Hari Tandri 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. These appointments are billed to your health insurance. To schedule an appointment, contact Crystal.

### Tele – Genetic Counseling

As we mentioned in the summer, we have taken steps to expand our clinical services via telemedicine for those unable to travel to Baltimore. This service currently consists of the genetic counseling/genetic testing appointment only. We hope to be able to offer second opinion consultations with our physicians in the future. Telemedicine appointments are currently not billable to your insurance company and require payment out of pocket. This service may not be available in certain states. To schedule an appointment, contact Crystal.

### Pediatrics

The world's only specialized Pediatric ARVD/C Clinic began in the Fall 2015. This is a monthly clinic staffed by a genetic counselor, Brittney Murray, and our pediatric ARVD/C specialist, Dr. Jane Crosson, pediatric electrophysiologist. We will offer second opinions/consults for both patients possibly affected and also cardiac testing associated with screening for family history of ARVD/C. Contact Crystal for information regarding upcoming dates for this specialty clinic.

Crystal Tichnell, MGC

[ctichnell@jhmi.edu](mailto:ctichnell@jhmi.edu)

410-502-7161

## Research Opportunities at Johns Hopkins

### Relative Safety, Efficacy, and Patient Satisfaction of Standard ICDs versus the Sub-Cutaneous ICD

**Who can participate?** Patients diagnosed with ARVD/C and have:

- ✓ S-ICD implanted
- ✓ Transvenous ICD implanted after January 2013

**What do I have to do?** Contact Crystal ([ctichnell@jhmi.edu](mailto:ctichnell@jhmi.edu)).

You will need to sign a consent form, send us your medical records, and complete online questionnaires.

**Do I have to travel to Johns Hopkins?** No

**Once enrolled, please remember to check your email for reminders to complete the online questionnaires. It is really important that we continue to collect this follow up data. Thank you for your participation.**

Sponsored by Boston Scientific  
PI: Hugh Calkins, MD  
Johns Hopkins IRB NA\_00042471 (*Predictors of Implantable Cardioverter Defibrillator (ICD) Firing in Right Ventricular Dysplasia*)

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

**Who:** Children and Adults with ARVD/C

**What:** Collection of pertinent past medical records and continued collection for 5 years. A blood sample for DNA for genetic mapping of ARVD/C genes will also be collected.

**How to Join:** Contact Crystal at 410.502.7161 or [ctichnell@jhmi.edu](mailto:ctichnell@jhmi.edu).

### Have you had an epicardial ablation?

We are looking for people with ARVD/C who have had an epicardial ablation to join our Registry. Help us discover how this new technique affects the course of ARVD/C! Contact Crystal at 410-502-7161 or [ctichnell@jhmi.edu](mailto:ctichnell@jhmi.edu)

### Outcomes of genetic counseling for arrhythmogenic cardiomyopathy: A comparison of face-to-face and tele-genetic counseling

As we've mentioned before, we are now offering tele-genetic counseling! We are taking this opportunity to determine whether genetic counseling services offered via telephone/videoconference differs from the traditional face-to-face genetic counseling. As mentioned above, insurance coverage is lacking for telemedicine visits, so more evidence is needed to document the utility of this service!

Data will be collected by completing questionnaires 2 weeks preceding and 2 weeks following a genetic counseling session for an arrhythmogenic cardiomyopathy indication. Results of the study will provide some of the first evidence of genetic counseling outcomes in cardiology clinics, and also contribute outcome data of alternative methods to expand genetic counseling services.



## 2017 Publications

- Te Riele ASJM, Agullo-Pascual E, James CA, Leo-Macies A, Cerrone M, Zhang M, Lin X, Lin B, Sobreira NL, Amat-Alarcon N, Marsman RF, Murray B, Tichnell C, van der Heijden JF, Dooijes D, van Veen TAB, Tandri H, Fowler S, Hauer RNW, Tomaselli G, van den Berg MP, Taylor MRG, Burn F, Sinagra G, Wilde AAM, Mestroni L, Bezzina CR, Calkins H, van Tintelen JP, Bu L, Delmar M, Judge DP. Multilevel analyses of SCN5A mutations in arrhythmogenic right ventricular dysplasia/cardiomyopathy suggest noncanonical mechanisms for disease pathogenesis. *Cardiovasc Res.* 2017;113(1):102-111.
- Mast TP, James CA, Calkins H, Teske AJ, Tichnell C, Murray B, Loh P, Russell SD, Velthuis BK, Judge DP, Dooijes D, Tedford RJ, van der Heijden JF, Tandri H, Hauer RN, Abraham TP, Doevendans PA, te Riele ASJM, Cramer MJ. Structural progression in arrhythmogenic right ventricular dysplasia/cardiomyopathy. *JAMA Cardiol.* 2017;2(3):293-302.
- Bhonsale A, Te Riele AS, Sawant AC, Groeneweg JA, James CA, Murray B, Tichnell C, Mast TP, van der Pols MJ, Cramer MJ, Dooijes D, van der Heijden JF, Tandri H, van Tintelen JP, Judge DP, Hauer RN, Calkins H. Cardiac phenotype and long-term prognosis of arrhythmogenic right ventricular cardiomyopathy/dysplasia patients with late presentation. *Heart Rhythm.* 2017;Feb 12. doi: 10.1016/j.hrthm.2017.02.013 (Epub ahead of print).
- Fiallos K, Applegate C, Mathews DJ, Bollinger J, Bergner AL, James CA. Choices for return of primary and secondary genomic research results of 790 members of families with Mendelian disease. *Eur J Hum Genet.* 2017;25(5):530-537.
- Gupta R, Tichnell C, Murray B, Rizzo S, Te Riele AS, Tandri H, Judge DP, Thiene G, Basso C, Calkins H, James CA. Comparison of features of fatal versus non-fatal cardiac arrest in patients with arrhythmogenic right ventricular dysplasia/cardiomyopathy. *Am J Cardiol* 2017. doi: 10.1016/j.amjcard.2017.03.251(Epub ahead of print).
- Haggerty CM, James CA, Calkins H, Tichnell C, Leader JB, Hartzel DN, Nevius CD, Pendergrass SA, Person TN, Schwartz M, Ritchie MD, Carey DJ, Ledbetter DH, Williams MS, Dewey FE, Lopez A, Penn J, Overton JD, Reid JG, Lebo M, Mason-Suares H, Austin-Tse C, Rehm HL, Delisle BP, Makowski DJ, Mehra VC, Murray MF, Fornwalt BK. Electronic health record phenotype in subjects with genetic variants associated with arrhythmogenic right ventricular cardiomyopathy: A study in 30,716 subjects with exome sequencing. *Genet Med.* 2017. May 4. doi: 10.1038/gim.2017.40. (Epub ahead of print)
- Orgeron G, James CA, te Riele AS, Tichnell C, Murray B, Bhonsale A, Kamel I, Zimmerman S, Judge DJ, Crosson J, Tandri H, Calkins H. Implantable cardioverter defibrillator therapy in arrhythmogenic right ventricular dysplasia/cardiomyopathy: Predictors of appropriate therapy, outcomes and complications. *J Am Heart Assoc* 2017; 6:e006242.
- Gilotra N, Bhonsale A, James CA, te Riele ASJ, Murray B, Tichnell C, Sawant A, Ong CS, Judge DP, Russell SD, Calkins H, Tedford RJ. Heart failure is common and under-recognized in patients with arrhythmogenic right ventricular cardiomyopathy/dysplasia. *Circ Heart Fail* 2017. DOI: 10.1161/CIRCHEARTFAILURE.116.003819 (Epub ahead of print)
- Rhodes AC, Murray B, Tichnell C, James CA, Calkins H, Sears SF. Quality of life metrics in arrhythmogenic right ventricular cardiomyopathy patients: The impact of age, shock, and sex. *Int J Cardiol.* 2017;19(1)
- Bourfiss M, Vigneault DM, Aliyari Ghasbeh M, Murray B, James CA, Tichnell C, Mohamed Hoesein FA, Zimmerman SL, Kamel IR, Calkins H, Tandri H, Velthuis BK, Bluemke DA, te Riele ASJM. Feature tracking CMR reveals abnormal strain in preclinical arrhythmogenic right ventricular dysplasia/cardiomyopathy: A multisoftware feasibility and clinical implementation study. *J Cardiovasc Magn Reson.* 2017;19:66.
- Berrios C\*, James CA\*, Raraigh K, Bollinger J, Murray B, Tichnell C, Applegate CD, Bergner AL. Enrolling genomics research participants through a clinical setting: The impact of existing clinical relationships on informed consent and expectations for return of research results. *J Genet Counsel.* 2017; doi: 10.1007/s10897-017-0143-2. (Epub ahead of print).

## How You Can Help

### Your Support of the Johns Hopkins ARVD/C Program Ensures Our Success

As a charitable, tax-exempt organization, Johns Hopkins Medicine relies on donations to make a difference in the lives of our patients. Supporters of Dr. Calkins, Dr. Tandri, and their team of experts in the ARVD/C Program, become part of our mission to provide exceptional personalized care and to find better ways to diagnose and treat our patients. Here are some of the many ways that you can help:

#### Make a Donation

Donations of all sizes, whether they're one-time or recurring, make a difference and can be made online at [www.arvd.com](http://www.arvd.com), by phone at 443-287-7382, or by mail (information listed below). There are a variety of ways to make a gift to support our efforts in the ARVD/C Program:

- Make an outright gift of cash or securities
- Become a monthly donor
- Give in honor or in memory of a loved one
- Give through IRA's, wills and trusts
- Leverage matching gifts through your workplace

#### Fundraising

There are many opportunities to become personally involved in raising awareness and much-needed funds on behalf of the Johns Hopkins ARVD/C Program:

- Create an online giving page and leverage social media
- Ask friends to make contributions in lieu of gifts
- Host your own event or auction
- Plan a fundraising event in your community or school
- Contribute a portion of your company's sales

#### The Johns Hopkins Heart and Vascular Institute Development Office is here to help!

We welcome your questions, concerns, ideas, and feedback. Please contact **Adrienne Rose**, Senior Associate Director of Development, at 443-287-7382 or [arose25@jhmi.edu](mailto:arose25@jhmi.edu), for more information.

#### Gifts by Mail:

The Johns Hopkins Heart and Vascular Institute  
600 North Wolfe Street, Blalock 536B  
Baltimore, MD 21287

**\*Indicate the "ARVD/C Program" on the memo line**

## ARVD/C Program Info

### ARVC Program Staff

Hugh Calkins, MD—Director  
Harikrishna Tandri, MD—Co-Director  
Cynthia James, ScM, PhD—Genetic Counselor  
Brittney Murray, MS—Genetic Counselor  
Crystal Tichnell, MGC—Genetic Counselor  
Anna Burton—Genetic Counselor Assistant  
Giovanna Jimenez—Clinic Coordinator  
Raymond Black—Insurance Specialist  
Julia Agafonova—Research Assistant

**Don't forget to keep us informed of your most up-to-date contact info!**  
**Please send any changes and updated medical records to Crystal via Fax: 410-502-9148 or email [ctichnell@jhmi.edu](mailto:ctichnell@jhmi.edu)**  
**You can also mail records as well.**  
**Thank you!**

### Contact Us

Johns Hopkins Hospital  
600 North Wolfe Street, Blalock 545  
Baltimore, Maryland 21287  
P: 410-502-7161, F: 410-502-9148  
Website: [www.ARVD.com](http://www.ARVD.com)

## Support Group Info

### Looking for a support group?

#### **FACEBOOK Groups (private):**

- ARVD/C Youth Society
- Hope for ARVD
- The Broken Heart Club – ARVD Edition –
- ARVC can't stop me from...

#### **ARVD/C Mentor Program:**

Get matched with an ARVD/C mentor!

Connect with a mentor who has navigated the challenges of life with ARVD/C and receive:

- Support
- Connection
- Understanding
- Strategies for Thriving with ARVD/C.

Contact Nancy Bogle at [nbstjohn@gmail.com](mailto:nbstjohn@gmail.com) for more information and visit [ARVDHEARTANDSOUL.org](http://ARVDHEARTANDSOUL.org)

