

JOHNS HOPKINS ARRHYTHMOGENIC RIGHT VENTRICULAR DYSPLASIA PROGRAM

Volume 1, Issue 1

Winter 2012

* ** ***!!!SEASONS GREETINGS!!!*** ** *

In this Issue...	page
2012 ARVD Family Seminar	2
Abstracts/ Presentations	3, 4
Research Opportunities	3
Patient Stories	5
Upcoming Fundraisers	6
Make a Donation	6
Support Group Info	6
ARVD Program Contact Info	6

We hope you and your families have had a wonderful Holiday Season and are looking forward to the New Year! The ARVD Program has been hard at work and would like to thank all of our patients and research participants for eagerly volunteering for our many research projects. Without each of you, we would not be in a position to continue our research efforts aimed at unraveling the many mysteries of ARVD/C. We appreciate the continued enthusiasm and thoughtful questions that you bring to our program. It is our goal to improve the diagnosis and treatment of ARVD/C which will allow you, the patients and families, to continue living the most fulfilling, productive lives that you have always envisioned. As always, we are available for consultations and evaluations in order to determine the best management strategies for you. Please do not hesitate to contact our program with any questions or concerns. We look forward to seeing many of you at our upcoming Patient & Family Seminar in April 2012. Details are enclosed. Best wishes to each of you for a Healthy 2012!

~ The ARVD Program

The Johns Hopkins Hospital New Clinical Building

If you haven't heard, Johns Hopkins Hospital is expanding! A new 1.6 million-square-foot hospital featuring two 12-story towers will open in early January. The cardiovascular and critical care tower will be the home of the new Johns Hopkins Heart Institute. The other tower will house the Charlotte R. Bloomberg Children's Center. The towers will include the following: 560 private inpatient beds (355 for adults and 205 for children), pediatric trauma service, pediatric burn service, indoor play area, modernized emergency departments, modernized diagnostic imaging and radiology facilities, and 33 state-of-the-art operating rooms, including 14 for neurosurgery/general surgery, 10 for pediatric, 6 for cardiac and 3 for obstetrics. We will expand to four state-of-the-art EP laboratories and a new MRI scanner dedicated for cardiac use. The next time you visit Johns Hopkins, you may receive your care in the new facilities at Johns Hopkins Hospital. Outpatient services will continue at the Johns Hopkins Outpatient Center.

2012 ARVD Patient & Family Seminar

It's that time of year again and we are excited to announce our annual ARVD Patient & Family Seminar to be held on April 28th, 2012. This is a great opportunity to meet others affected by ARVD/C and to learn the latest advances. Topics and presenters include: Thirty Years of ARVD/C (Hugh Calkins, MD), MR Imaging (Hari Tandri, MD), Genetics (Dan Judge, MD), The Science of ARVD/C (Mario Delmar, MD), Catheter Ablation (Hari Tandri, MD), Heart Failure and Transplant (Stuart Russell, MD), and Living with a Chronic Condition (Stefanie Toise, PhD). In addition, there will be afternoon workshops on Genetic Testing, Question and Answer with the Experts, Healthy Living Workshop to include Nutrition and Yoga, and an Under 25 self-led Youth Group. There will also be opportunities to participate in research. We have an exciting and packed agenda so we hope to see many of you in April! Specific details are enclosed. Please register early!



Abstracts and Presentations

DOES FAMILY HISTORY INFLUENCE ANXIETY AND DEPRESSION LEVELS AMONG ARRHYTHMOGENIC RIGHT VENTRICULAR DYSPLASIA/CARDIOMYOPATHY (ARVD/C) PATIENTS?

Leila Jamal, Crystal Tichnell, Brittney Murray, Samuel Sears, Hugh Calkins, Cynthia James

The purpose of this study was to determine how the presence of a family history of ARVD/C affects psychosocial adjustment of having a diagnosis of ARVD/C. Of 86 adults enrolled in the Johns Hopkins ARVD Registry, 34 (40%) met family history diagnostic criteria for ARVD/C. Enrollees completed a series of questionnaires that assessed anxiety, depression, function capacity, and quality of life. Those with a positive family history for ARVD/C were less likely to have clinically significant anxiety, thus, having a family history may be protective against clinically significant anxiety and depression in ARVD/C patients. Further research into the mechanism for this protective effect may enhance genetic counseling for inherited cardiac disease.

Abstracts and Presentations

Dr. Jeremy Burt received the Cum Laude award for his abstract entitled, *Pitfalls in Evaluation of the Right Ventricle at Cardiac MRI: How to Avoid Misdiagnosis of ARVD*, at the 97th Scientific Assembly and Annual Meeting of the Radiological Society of North America held November 27-December 2, 2011 in Chicago, Illinois.



Feel the Beat Feel the Beat Feel the Beat Feel the Beat

The "Feel the Beat" section of the newsletter is dedicated to patient stories. If you would like to share your story in a future newsletter, contact Crystal at ctichnell@jhmi.edu

ARVD Program Staff



ARVD Program Staff

Hugh Calkins, MD—Director
Harikrishna Tandri, MD—Faculty
Daniel Judge, MD—Faculty
Stuart Russell, MD—Faculty
Theodore Abraham, MD—Faculty
Aditya Bhonsale, MD—Post Doctoral Research Fellow
Binu Philips, MD - Post Doctoral Research Fellow
Cynthia James, ScM, PhD—Genetic Counselor
Brittney Murray, MS—Genetic Counselor
Crystal Tichnell, MGC—Genetic Counselor

Contact Us

Johns Hopkins Hospital
600 North Wolfe Street, Carnegie 530
Baltimore, Maryland 21287
P: 410-502-7161, F: 410-502-9148
Website: www.ARVD.com

We recently learned that the ARVD program - as part of a large group of genetic researchers at Johns Hopkins - will receive funding from the National Institutes of Health to use new genetic technologies to look for new ARVD-associated genetic mutations. Stay tuned for more information on this exciting project.

How You Can Help

Healing Hearts

7th Annual Bull & Oyster Roast

Friday, February 10th, 2012

7:00 pm - midnight

American Legion, 109 Dewey Lowman
1610 Old Sulphur Spring Road
Arbutus, MD 21227

Tickets are \$40 per person. Proceeds to benefit ARVD Research at Johns Hopkins Heart Institute. There will be raffles including a \$500 grand prize, a silent auction and more! For additional information, to reserve a table or purchase tickets, please email HealingHeartsMD@yahoo.com. Visit www.HealingHeartsMD.com for info regarding this organization and events.

Looking for a support group?

Visit: www.arvd-arvd-info.com

What would you like to see in the next newsletter?

Email Crystal with your ideas
ctichnell@jhmi.edu