

Enrolling now: A new study offers convenience, control, and quality of life

Do you ever wonder how information from your testing in the Human Performance Lab is used to help childhood cancer survivors stay healthy?

A series of SJLife studies have used results from the lab to look for links between survivors' heart function, cancer treatments, perceptions of well-being, and exercise intolerance. "Exercise intolerance" means difficulty in moving around in one's daily life—for example, climbing stairs or walking across a parking lot. Exercise intolerance can put a person at risk for serious health effects, but fortunately, exercise intolerance is also something that can be changed.

In these studies, Dr. Kirsten Ness and her team found that exercise intolerance was more common than expected, affecting 64% of survivors who received cancer treatments linked to higher risk of heart problems versus 56% of survivors who did not receive these treatments. Also, compared to those [cont. on page 4](#)



Justin Venemon, Biomedical Photographer (St. Jude Children's Research Hospital)

Intervention Exercise Specialist Bruce Wolcott demonstrates a dumbbell biceps curl in the HOME HEART HEALTH virtual exercise training room on the St. Jude campus.

Dear SJLife Study participants,

Just as we're sure is the case for all of you, we are looking forward to a new year and especially to the time we can gather in person with family and friends. The whole SJLife team has also missed seeing you on campus.

While the pandemic will clearly still restrict these activities in the coming

months, we want to reassure you that the SJLife study has continued to make progress in advancing our understanding about health after childhood cancer (see page 3 for some examples of our research activities during the pandemic).

Over the last year we have increased our efforts to use remote platforms to stay in touch with you, understand your ongoing health concerns and challenges, and continue research. Featured in this issue of the LIFELINE is the newly opened HOME HEART HEALTH exercise intervention study that will be con-

ducted completely remotely by exercise specialists—meet a few of them in the profile on page 2.

We are always happy to hear from you. Please stay in touch and share your feedback about this issue, topics you'd like to see in future issues, and anything else on your mind! Call us at 800-775-2167, or email us at sjlife@stjude.org.

- Melissa M. Hudson, MD
Co-Principal Investigator, SJLife Study
- Les L. Robison, PhD
Co-Principal Investigator, SJLife Study

FROM THE **study team**



Meet the HOME HEART HEALTH team

Q&A with exercise specialists



Robyn Partin
MS, CEP, CCRP



Sean O'Neil
MA, RCEP

Robyn Partin and Sean O'Neil share their passion for exercise science and excitement about the HOME HEART HEALTH study

Why did you become an exercise specialist?

RP: I've been an athlete since I was 4 years old and was always interested in sports and exercise. In college, I took Introduction to Exercise Science and fell in love with it—it was one of the classes I got an A+ in because I read the book cover to cover! Once I finished my undergraduate degree, I went on to a master's program at the University of Memphis, where I got to dig deep into the research side of things. I've been

at St. Jude Children's Research Hospital for 11 years now and am the director of the Human Performance Lab.

SO: Being in athletics my whole life (but not as accomplished as Robyn, our Division 1 diver!), I went to college considering sports medicine or physical therapy. Central Michigan has a great exercise science program. And the more I worked with clinical populations, the more interested I became in helping people who weren't athletes who could really benefit from exercise. After a 2-year graduate assistantship, I was lucky enough to land a job at St. Jude, and it's been awesome working with SJLife participants. With studies like HOME HEART HEALTH, we get to push the boundaries of what we can do and how we can help cancer survivors.

What excites you about the HOME HEART HEALTH study?

RP: I'm excited we're doing something completely new. Exercise specialists and physical therapists are usually hands-on, but we don't get to be with this study. When I train new staff I already emphasize communication—you have to say exactly what you mean, because people can interpret instructions differently. Now, without being in person, the importance of

verbal communication is even greater, which will only strengthen our skills.

SO: I'm excited to introduce exercise to more of our patients. A lot of survivors don't exercise and become frail at a younger age. Since SJLife participants return for the SJLife Study, we'll be able to see improvements over time. What we learn from a study like this also has the potential to benefit childhood cancer survivors across the country.

What technology is involved?

SO: Participants will receive an iPad with a program that has Zoom chat capability for exercise sessions, heart rate monitoring, their schedule, previous session information, and exercise videos. The exercise specialists doing the testing will run through everything with participants and show them how to use it. It's really simple, easy-to-use software, so even people who don't feel comfortable with technology will be able to understand quickly and easily.

What would you say to someone who thinks they can't exercise?

RP: Many people are hesitant to start exercising because they've had bad experiences. There's definitely a better way to get into shape in a

Exercise specialists



Amy Kozerski, MS, CEP



Bruce Wolcott, MS, CEP



Matt Wogsch, MS, CEP



Michelle Tollakson,
PT, DPT, OCS

Study coordinators



Sarah Terrell



Matt Krull

Study nurses



Rhonda G. Okoth,
MPH, BSN, RN, CCRP



Kat Zelinka, BSN, RN



Dr. Kirsten Ness,
principal investigator

and start them at a comfortable level. We're going to find something they enjoy that will get their heart rate up and work on building strength. We want people to look forward to the session and see some results.

I think the pandemic allows people to say—'You know what, I can do that; I can take my lunch break and do it, or my schedule is so flexible that I can work it in during the day and not have to do it at 5 a.m. or 8 p.m.' And it's a way to have more interactions with new people. Even though it's virtual, it's something that can bring a new perspective to your day.

SO: If you are afraid of gyms or don't know where to start, this is an easier way to start exercising that is completely personalized. You'll talk with us about your goals; it's built on what you want to do. We're a pretty relaxed, upbeat group, so it's going to be fun. We'll hopefully change the way you think about exercise.

If you are interested in the study, reach out to us at HomeHeartHealth@stjude.org because even if it won't work with your schedule now, maybe it'll work better in the spring or the summer. Talk to us about the barriers you think might be an issue, and we can help figure out if it's the right fit.

safe and comfortable manner. I don't mean that it will never be difficult—it's sort of the point of exercise to sometimes make things a little challenging. The exercise specialist will look at the person's test results

SJLIFE COMMUNITY

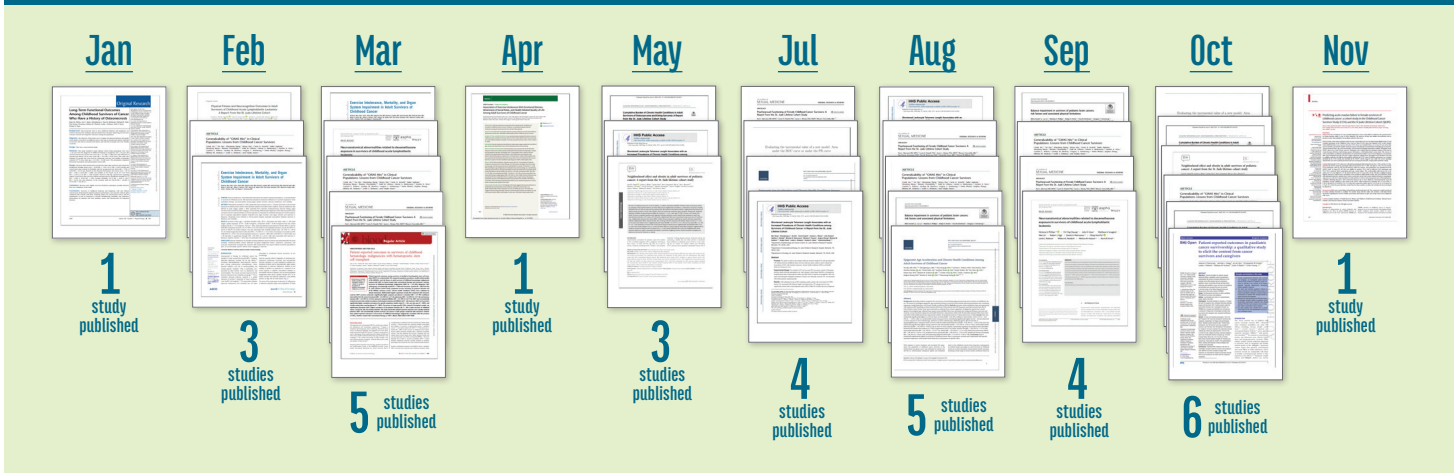
SJLife research activity during the pandemic

Despite the challenges brought to most every area of our lives during the pandemic, SJLife research efforts continue unabated.

As the graphic below shows—thanks to your ongoing participation in SJLife—between January 1, 2020, and early December 2020, 33 research articles related to SJLife have been published, 18 SJLife research grants have been submitted with 6 already funded, 9 SJLife research projects are

underway, and 12 new projects launched in 2020. We hope this gives you some sense of how vital your participation continues to be and the research that you make possible. Some of the new studies (like HOME HEART HEALTH) are offered remotely, and you may hear from us about participation.

During 2020, SJLife published 33 research articles in scientific journals:



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| Also in 2020: | Active/continuing projects in 2020 from previously (pre-2020) funded grants: 9 | Projects begun in 2020: 12 | Grants submitted in 2020 (6 already funded): 18 |
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Dr. Hudson wins award for outstanding contributions to childhood cancer survivorship

Melissa M. Hudson, MD, director of the Division of Cancer Survivorship at St. Jude Children's Research Hospital and co-PI of the SJLife Study, was selected as the 2020



recipient of the Northwestern Mutual Award for Excellence in Childhood Cancer Survivorship by the American Society of Pediatric Hematology/Oncology (ASPHO). The annual award honors an individual for outstanding contributions to the field of survivorship in pediatric hematology/oncology.

"The overarching goal of survivorship research is to help survivors achieve the

best possible health and quality of life after the childhood cancer experience," Dr. Hudson says. "It has been incredibly rewarding to participate in both clinical and research efforts that have positively influenced outcomes of long-term survivors of childhood cancer and informed safer therapies for newly diagnosed children with cancer."

New exercise study *cont. from page 1*

with exercise intolerance, survivors with higher exercise capacity reported better emotional and physical well-being. These study findings support the importance of developing an exercise intervention study to help both physical and emotional health.

Study details

Launching in early 2021, the HOME HEART HEALTH study, which is 100% remote, plans to enroll 160 SJLife participants between 18 and 40 years old who have exercise intolerance. Participants will be randomly assigned to one of two groups for 20 weeks, to receive either an individualized exercise program or generalized exercise recommendations. The study goal is to determine which approach best promotes increased physical activity in survivors.

Participants who are randomized to the

individualized exercise program will receive a tailored exercise prescription written by an exercise specialist assigned to them, who will lead them in online exercise sessions (see article on page 2). The prescription will be based on an online assessment by an exercise specialist and by participant personal preferences. The program will include aerobic and strengthening exercises that will gradually increase in time and intensity.

"Often when survivors see a health professional, they are told, 'You should exercise 30 minutes, 5 times a week so you sweat or breathe hard,' but that's probably not enough guidance. We need to meet survivors at their current exercise level," says Dr. Ness.

Participants will receive (and get to keep) everything they need to participate remotely, including detailed instructions, a heart rate monitor, all of the necessary exercise equipment, and an iPad pre-loaded with the intervention app.

Participants randomized to the control group will also receive an assessment, as well as exercise guidance and weekly online check-ins and encouragement from study staff. At the end of the study, survivors randomized to receive standard exercise guidance will be offered the opportunity to participate in the individualized exercise program (for no charge).

Study appeal

Dr. Ness is optimistic that the telehealth exercise intervention study will be well received. "While survivors had zero control over getting cancer in the first place, participation

Call to participants: We need your input!

The SJLife team is committed to making participants' study experience as rewarding as possible, and we sometimes find ourselves wishing we could ask you, "What do you think?"

Participants who are willing to share their opinions and ideas are invited to become part of a new SJLife Study Participant Advisory Council (PAC). Any participant can volunteer to be available for possible contact when questions arise that would benefit from your perspective. We hope PAC volunteers will also proactively share their feedback with us.

Volunteering for the PAC doesn't require a time commitment. We'll reach out, on an as-needed basis, to people who have signed up. If we contact you and you have a lot going on, you can say, "Sorry, next time."

To volunteer, please contact us at 800-775-2167 or sjlife@stjude.org.

in the study will give them an opportunity take control over their own health," says Dr. Ness.

Also, most people have been spending a lot of time at home during the pandemic and may be eager for new things to do.

Per Dr. Ness, "Because we can adapt the exercise intervention, even survivors with chronic health problems that contribute to exercise intolerance can benefit from participation."

If you're interested, want to know if you meet the eligibility criteria, or just want more information, reach out to the study team at HomeHeartHealth@stjude.org.

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| LIFeline | SJLife St. Jude Lifetime Cohort Study |
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Please stay in touch!

Call us: 800-775-2167

Email us: sjlife@stjude.org

Visit our website: www.stjude.org/sjlife-participate