

## Genetic testing for SJLife Study participants

As knowledge of genetics and genetic testing has advanced, information is now available that may be helpful for you, including steps to protect your health.

With the rise of popular at-home genetic testing (like 23andMe), people are now able to get information about their own genetics, including potential disease risks. And genetic results may be even more beneficial for cancer survivors, who can have increased health risks from their cancer and/or treatments.

Genetic testing also can help clinicians better understand any health risks you may have and help to take better care of you.

### Free genetic testing

Your participation in the SJLife Study has helped improve understanding about how genetics affect a survivor's risk for health problems later in life (see "Research updates" on page 3).

St. Jude is now offering clinical genetic

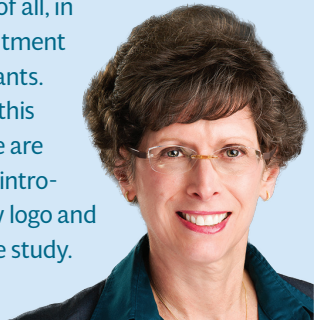
testing to all SJLife Study participants at no cost. Unlike research genetic testing, results from clinical genetic testing can be used by survivors, their families, and healthcare team to make medical decisions.

To offer information about clinical genetic testing, we have started contacting SJLife participants by email and telephone, and will be reaching out to all participants in the coming year. Some participants were offered and had

*cont. on page 4*



**Dear SJLife Study participants,**  
Over the past 13 years, the SJLife Study has expanded—in sheer numbers, in the ambitions of our research, and, most of all, in the commitment of participants. Reflecting this growth, we are pleased to introduce a new logo and look for the study. We think it



### From the study team

captures the energy and optimism of everyone involved in this effort, and hope you agree.

Just as the COVID-19 pandemic has touched so many lives, it has had a large impact on the SJLife Study as well. Starting March 5, to protect participants, we stopped on-campus SJLife Study evaluations, elective clinic appointments, and in-person research activities. While these activities are paused until we feel it is safe to resume, data from your participation is safely saved. SJLife researchers are using this time to complete papers and organize new research projects. Your previous and future contributions to our research are more important than ever. In the midst of the uncertainty we are all experiencing, what is unwavering is our commitment, concern, and caring for you.

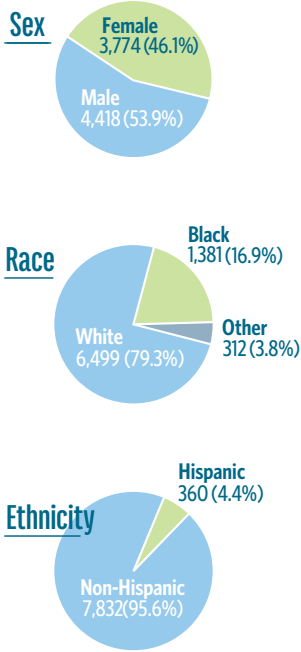
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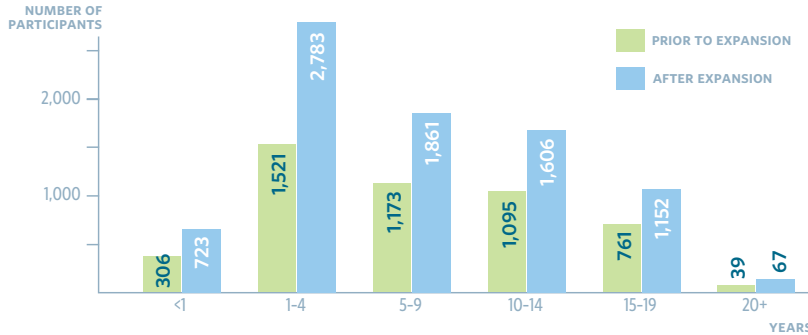
# SJLife Study by the numbers

Demographic details about SJLife Study participants—such as age, gender, ethnicity, and more—offer a snapshot of what the SJLife Study community looks like.

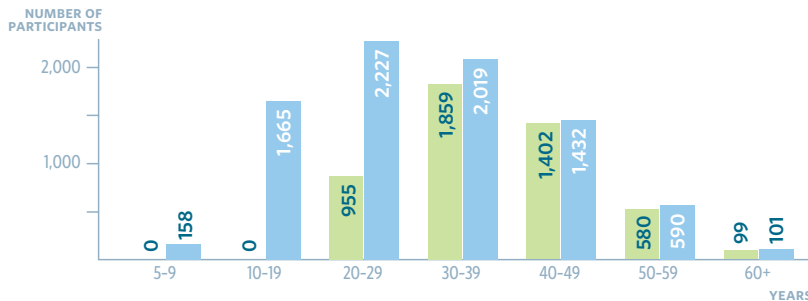
The SJLife Study began in 2007 with St. Jude patients who were ages 18 years and older and 10 years since their diagnosis. In 2015, the study expanded to include all St. Jude patients who are 5 years past diagnosis (with no age limits).



## Age at diagnosis



## Current age



## Demographic highlights:

- In 2014, before the study expanded, the original study population was 4,895. After the expansion, the study population grew to 8,192 people!
- There are slightly more males than females in the study—nearly 54% male and just over 46% female.
- Since the study's expansion, the diversity of participants has grown and is now nearly 17% Black and nearly 4% other races. Hispanic participants make up over 4% of the population.
- The largest group of SJLife participants were 1-4 years old at diagnosis; the next-largest group were 5-9 years old, followed by 10- to 14-year-olds.
- Currently, the largest number of participants are 20-29 years old, then 30- to 39-year-olds, followed by 10- to 19-year-olds (all of whom joined after the expansion and now make up 20% of the population!).

## From the study team *cont. from page 1*

In brighter news, we are pleased to share that the National Cancer Institute approved continued funding of the St. Jude Lifetime Cohort Study, which demonstrates strong support for our work and the importance of our research, all of which you make possible.

We are always happy to hear from you. Please stay in touch and share your feedback about our new look, 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](mailto:sjlife@stjude.org).

—Melissa M. Hudson, MD  
Co-Principal Investigator, SJLife Study

—Les L. Robison, PhD  
Co-Principal Investigator, SJLife Study

## COVID-19 resources

While we are still learning about this virus, we know that some cancer survivors may be at higher risk for a severe course of COVID-19 and wanted to share some trusted resources:

- *Together*, St. Jude online resources, including COVID-19 information ([together.stjude.org/en-us/care-support/covid-19-resources.html](https://together.stjude.org/en-us/care-support/covid-19-resources.html))
- COVID-19 and Cancer Survivors, a tipsheet from the Children's Oncology Group (available in a few languages at [www.survivorshipguidelines.org](http://www.survivorshipguidelines.org))
- COVID-19 information for childhood cancer survivors from the International Guideline Harmonization Group (available in multiple languages at <https://www.ighg.org>)

Key  
paperGenetic risk for second cancers  
in childhood cancer survivors

**SJLife Study participants have again helped researchers to make key discoveries**—this time in the realm of genetics and risk for having one or more cancers.

Research has shown that survivors of childhood cancer are at a higher risk for chronic health conditions, including second cancers, due to their cancer treatment. But “the scope of genetic factors affecting the risk of second cancer has not been previously reported,” says Dr. Zhaoming Wang, lead author of the paper and a genetic epidemiologist at St. Jude.



Dr. Zhaoming Wang

## Why is this paper significant?

Dr. Kim Nichols, a co-author and director of the Cancer Predisposition Division at St. Jude, says, “We know that in rare instances cancer can run in families, and people can carry changes in the sequence of certain genes that puts them at risk for cancer. Getting a second cancer is a rare but very important health threat for cancer survivors. We were interested in learning whether genetic factors could increase the risk for second cancers.”

Understanding the genetic causes of cancer can help identify who could be most at risk for getting cancer. “At-risk people may benefit from more frequent cancer screening or may decide to have preventive surgeries, in some cases, to reduce or eliminate the risk for primary or second cancers altogether,” Dr. Nichols says.

## What was learned?

“We did whole genome sequencing for about 3,000 survivors in the SJLife Study. This method gives a large-scale and very detailed look at genetic changes (mutations) associated with increased risk for a variety of cancers,” says Dr. Wang.

The researchers found that about 6% of the survivors studied carried a mutation that is highly likely to

increase their second cancer risk. “Those mutations could also possibly explain why they developed cancer in the first place when they were a child,” says Dr. Wang.

## What do the findings mean for survivors?

**Consider genetic testing:** Finding that 6% of survivors had a mutation in a cancer predisposition gene and an increased risk of developing a second cancer means that survivors may benefit from genetic counseling and testing.

“Not every survivor who carries a mutation will develop a second cancer, but having this information can help a survivor make health decisions about cancer screening and preventive measures to reduce cancer risk,” says Dr. Wang.

**Family impact:** A genetic change (mutation) could be shared by family members and could be passed to children. So genetic counseling may also benefit survivors’ families and may affect family members’ decisions about cancer screening and prevention, as well as family planning.

**Journal of Clinical Oncology** Genetic Risk for Subsequent Neoplasms Among Long-Term Survivors of Childhood Cancer. *Journal of Clinical Oncology* 36, no. 20 (July 10, 2018) 2078-2087.



Dr. Kim Nichols

Genetic testing  
recommendations

Dr. Nichols recommends:

- Consult with a genetic counselor to discuss the risks and benefits of genetic testing for yourself and your family members. The decision to have genetic testing is personal and should not be rushed.
- Discuss plans for genetic testing with your spouse, grown children, and other family members before testing, because if a test is positive, the results could affect the family. A genetic counselor can help you and your family prepare for handling positive test results.

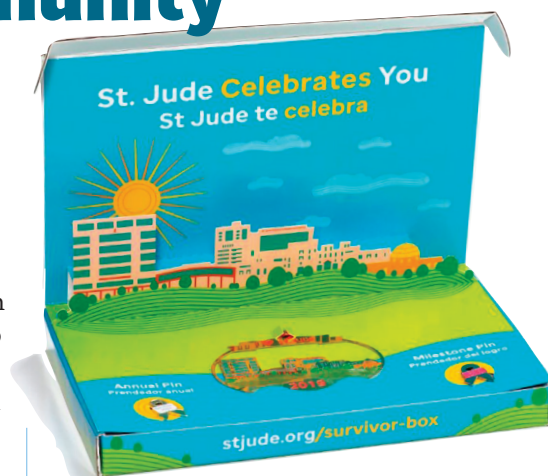
# Survivor Boxes celebrate St. Jude community

In 2018, St. Jude began a new program that quickly became an annual tradition: St. Jude Survivor Celebration Boxes.

Born out of Survivors' Day, a previous on-campus annual event at which St. Jude patients would receive a pin recognizing their survivorship, Survivor Boxes expand the reach of this celebration. In 2019, Boxes were sent to more than 9,500 survivors across the country.

This year's Boxes contained a guide with health updates and news from St. Jude, a metal skyline ornament, a 2019 survivor pin, and any other applicable milestone pins (Day 1, 5 years, 10 years, 25 years, 35 years, 50 years).

Patients shared an overwhelming amount



of positive feedback about the Boxes. Many posted photos to social media, proudly displaying their pins.

## 5,000th participant

From the St. Jude *Promise* magazine: The SJLife Study was honored to enroll its 5,000 participant, Lindsey Gruwell Headrick, who returned to St. Jude to take part in health screenings.

"By being in the SJLife Study, I'm giving back a little to St. Jude research, and I'm staying connected to the hospital," Lindsey explains. "What they gather from me might help improve treatment regimens or decrease lasting side effects of those who face this cancer journey." More at [www.stjude.org/SJLIFE-5K](http://www.stjude.org/SJLIFE-5K).

## SJLife in video

If you missed it, watch our short video celebrating SJLife Study's history and accomplishments, including receiving the American Association for Cancer Research Team Science Award:

[www.stjude.org/sjlife-10-plus-years](http://www.stjude.org/sjlife-10-plus-years).

# Genetic testing for participants *cont. from page 1*

testing while on site for their SJLife Study evaluation.

## Genetic counseling

SJLife Study participants can receive clinical genetic testing through a partnership with St. Jude and MyGeneTeam, which includes genetic counseling. "I am a strong advocate of doing genetic testing with the help of a genetic counselor," says Dr. Kim Nichols, director of the Cancer Predisposition Division

at St. Jude. "A genetic counselor can clearly explain the test, the possible results, what they could mean, and depending on results, can help guide you about what to do next."

The decision whether to have genetic testing is a personal one. It could give you useful information, but there could be effects of the information for you and your family. Genetic counselors will talk through the advantages and disadvantages of testing to help you make the decision that is best for you.

of therapy," says Dr. Nichols.

"Patients who carry certain gene changes may be at risk for other cancers. A special cancer screening plan may be advised to help find cancer at an earlier, more easily treatable stage," she adds. "For some gene changes that are linked to a higher risk of cancer, surgery or medication may be options to reduce risk."

## Genetic discrimination

Sometimes people have concerns about genetic discrimination and if it could put them at risk for losing insurance or their job. A law passed in 2008 called the Genetic Information Non-discrimination Act (GINA) protects people from health insurance companies and employers using their genetic information against them.

"For example, you can't be denied insurance, charged with higher insurance premiums, or be fired from a job based on your genetic testing results. However, GINA doesn't protect from discrimination when applying for life insurance or disability insurance," says Dr. Nichols.

## Testing and family

"Genetic conditions run in families, and many survivors have children of their own. Identifying whether they have a gene change that they may have passed on to their children has implications for whether their children need screening, or if their siblings, parents, or other relatives might also be at risk," says Dr. Nichols. "There is an excellent network of genetic counselors across the U.S.—if a participant tests positive, and other family members need to be tested, this could be coordinated with the help of a local genetic counselor."

## Influence on treatment and care

Identifying a genetic mutation may be important in planning medical care. "If you knew that someone had a change in certain genes earlier in the course of care, this information could be important for treatment planning and monitoring after completion

## For more information


If you are interested in genetic testing or have questions, contact: [SJLifeGenetics@stjude.org](mailto:SJLifeGenetics@stjude.org) or 901-595-1080 or 833-844-5547.

# LIFELINE

**SJLife** St. Jude Lifetime Cohort Study

*Principal investigators*

Melissa M. Hudson, MD    Les L. Robison, PhD



262 Danny Thomas Place, Memphis, TN 38105

### Please stay in touch!

**Call us:** 800-775-2167

**Email us:** [sjlife@stjude.org](mailto:sjlife@stjude.org)

**Visit our website:** [www.stjude.org/sjlife-participate](http://www.stjude.org/sjlife-participate)