

Can I learn about any new discoveries about my child's health?

Biorepository studies may include genetic testing to better understand how blood diseases, tumors and cancers grow and change over time. During genetic testing, specific germline mutations may be discovered, and these mutations may have the potential to impact the health of your child or other members of your family.

You may choose to be notified of any mutations found in your samples, but notification will not automatically be provided unless requested. Due to the volume of samples collected and the nature of research activity, we are unable to notify you if a scientific breakthrough is made thanks to your specific sample.

All, for your one.®



For more information:
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Biorepository

Division of Hematology,
Oncology, Neuro-Oncology
and Stem Cell Transplantation

 Ann & Robert H. Lurie
Children's Hospital of Chicago®



The Pediatric Hematology, Oncology, Neuro-Oncology and Stem Cell Transplantation Biorepository at Ann & Robert H. Lurie Children's Hospital of Chicago is advancing the study of childhood diseases by collecting, storing and testing biological samples (e.g., blood, saliva, tissue, bone marrow) which have the potential to further scientific research and unlock breakthroughs.

Families who choose to provide samples to the biorepository are helping to advance a mission of providing "bench to bedside" translational science, which is improving outcomes for those with blood disorders and childhood cancers.

How does my child's donation help research efforts?

Scientists are continually working to understand how a person's genes impact their health, susceptibility to disease and tolerance of medications. Access to biological samples is essential to developing new scientific breakthroughs.

How does my child donate a sample to the biorepository?

A sample is often taken as a routine part of clinical care (e.g., blood draw, tissue biopsy) and excess is disposed of at the end of treatment. Participation in a biorepository allows a leftover sample to be saved and used for research purposes instead of being destroyed. Your child will not undergo any additional invasive procedures for the sole purpose of joining the biorepository.

Your child may be asked to provide samples at various points in time during their care. It is important for scientists to understand how patients respond, or do not respond, to prescribed treatments.

If I do not donate to the biorepository, will it impact my treatment?

No. Lurie Children's is committed to providing the best possible treatment to all patients, regardless of enrollment in research initiatives. Participation is entirely voluntary, and you can choose to stop participating in research initiatives at any time. You can request that your child's unused samples be destroyed if you no longer consent for them to be held in the biorepository.



Who has access to samples, and who determines which studies are done?

Biorepository samples are only released to researchers who have obtained Institutional Review Board approval for a study and justified the need for using biological samples. An internal committee of clinicians, scientists and administrators review all sample requests. Research ideas are generated by scientists who have expertise related to their area of study.

Will my privacy be protected?

Upon donating a sample to the biorepository, your child's sample will be de-identified and coded with a unique identifier number. A variety of different tests may be conducted on the sample, including possibly genetic tests, and information will be deposited into controlled access databases, but your child's name will never be associated with the sample.

Your child's sample may be sent to other multi-institutional biorepositories where it can be included in larger studies than are possible at Lurie Children's; the sample will be labeled with a unique identifier that cannot be linked to you by any outside institutions.

