

BIOBANK

QUESTIONS and ANSWERS

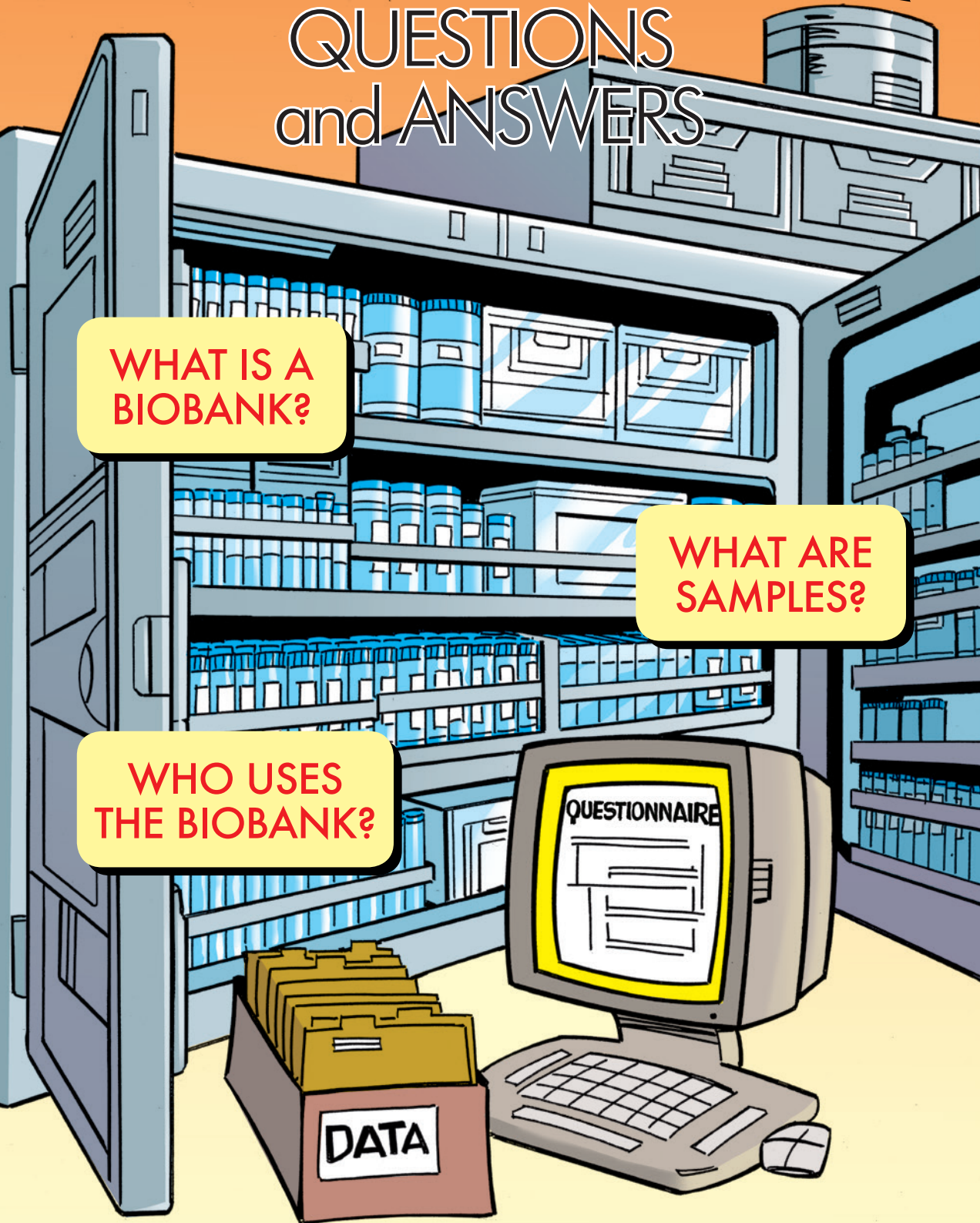
WHAT IS A
BIOBANK?

WHAT ARE
SAMPLES?

WHO USES
THE BIOBANK?

DATA

QUESTIONNAIRE





**Boston
Children's
Hospital**

WHAT IS A BIOBANK? AN INTRODUCTION FOR PARENTS. There are over 70 million children living in the United States, and millions of these children are affected by different illnesses. Chronic (long term) illnesses can be as mild as allergies or asthma, or as severe as cancer. Researchers across the world are working hard to identify the causes of these illnesses, so that they can discover and improve treatments. While major progress has been made in some areas, we still have a long way to go in other areas.

Researchers have realized that most chronic illnesses result from an interaction between genes and the environment. In the last 30 years, scientific methods have advanced to the point that we can easily characterize the genes (the inheritable material that transmits risk of disease from parent to child). Studying these genes has helped us develop better treatments for conditions like Crohn's disease, arthritis, epilepsy, and cystic fibrosis. Genetic research often requires samples from many children with an illness and their family members.

One important tool to support this type of research is a Biobank. When a patient comes in to see a doctor and a blood or tissue sample is obtained, part of that sample can be set aside in the Biobank for current or future research. With Biobanks, samples can be collected and shared with researchers across the world. This approach has many benefits. Sometimes only a few children across the world have a rare disease, and so sharing of samples between scientists in different hospitals can help speed new discoveries.

Participation in a biobank is voluntary, and individuals who donate their samples to a Biobank are asked to sign a consent form. Consent forms contain important information to consider before giving material to a Biobank. To help children and families understand Biobanks, we have developed the following illustrated guide. Through the expert educational team of Joe and Hilarie Staton and their colleagues, this pictorial monograph (aka comic book) illustrates what happens when a family is asked for a blood sample by a researcher, and how that sample is then stored and used. We hope that parents and children alike will enjoy this guide, and gain a better understanding of Biobanks and how they may contribute to curing diseases in the future.

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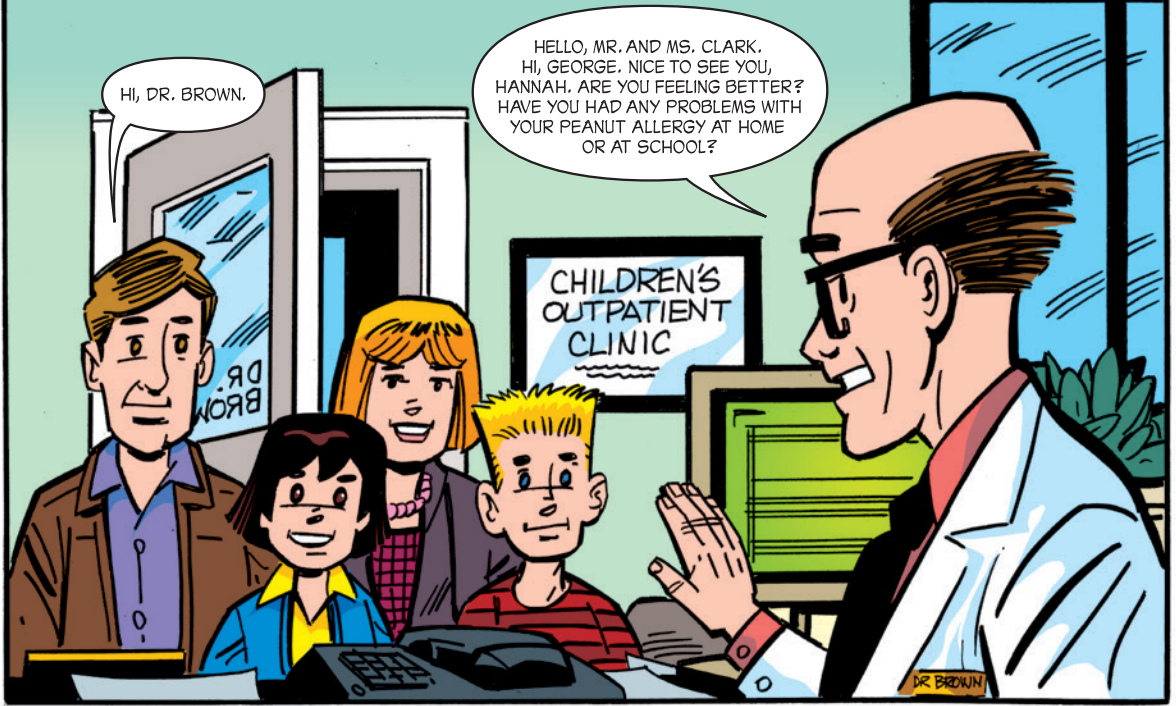
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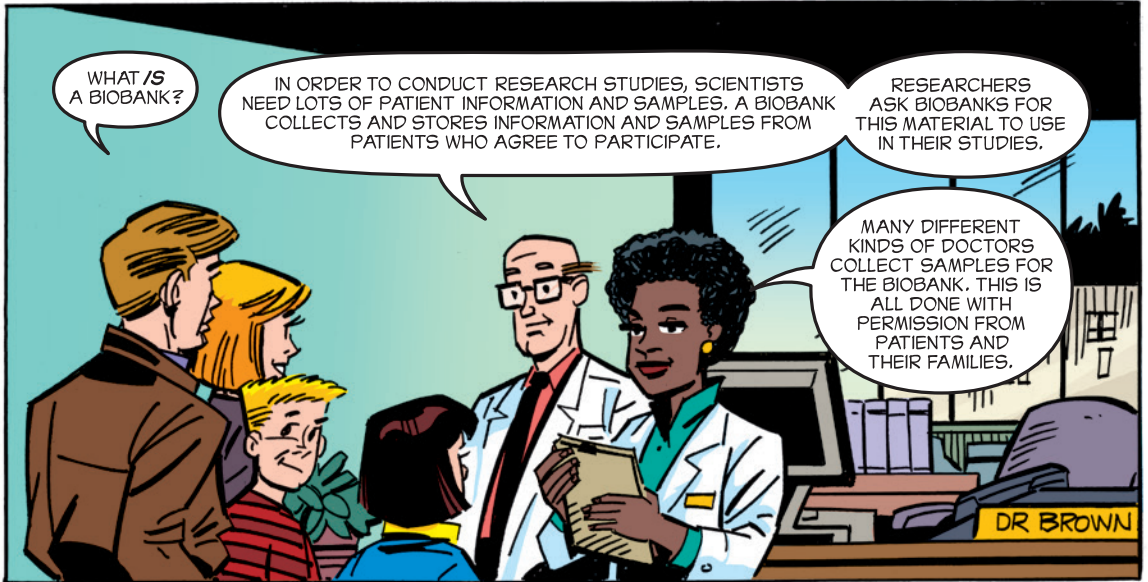
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Biobank

QUESTIONS & ANSWERS



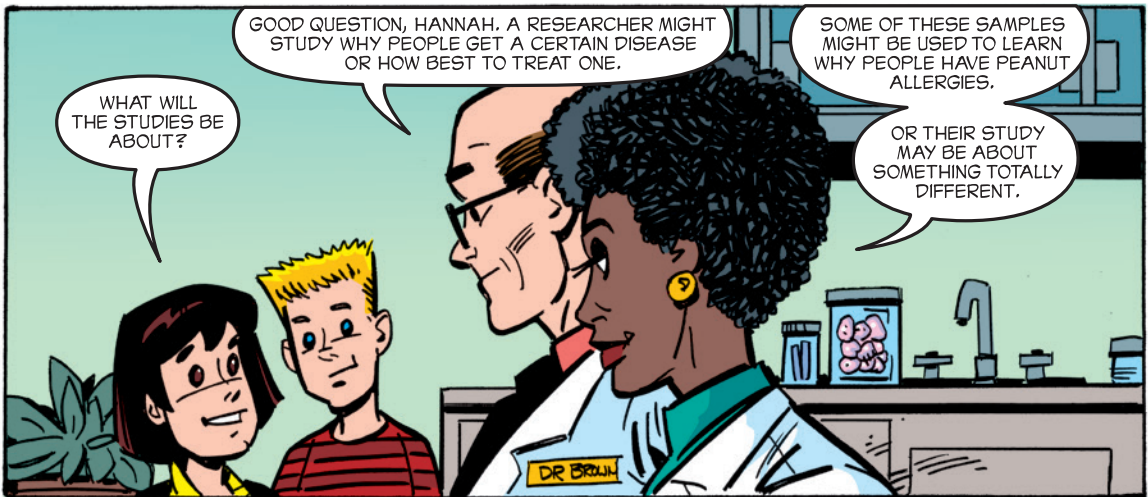


WHAT IS A BIOBANK?

IN ORDER TO CONDUCT RESEARCH STUDIES, SCIENTISTS NEED LOTS OF PATIENT INFORMATION AND SAMPLES. A BIOBANK COLLECTS AND STORES INFORMATION AND SAMPLES FROM PATIENTS WHO AGREE TO PARTICIPATE.

RESEARCHERS ASK BIOBANKS FOR THIS MATERIAL TO USE IN THEIR STUDIES.

MANY DIFFERENT KINDS OF DOCTORS COLLECT SAMPLES FOR THE BIOBANK. THIS IS ALL DONE WITH PERMISSION FROM PATIENTS AND THEIR FAMILIES.

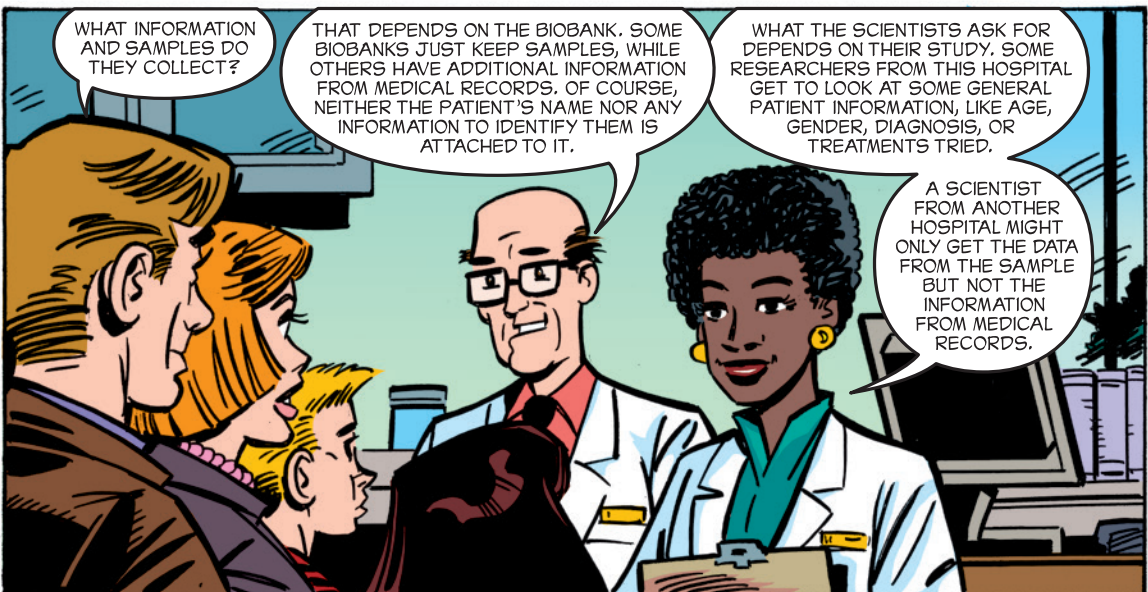


WHAT WILL THE STUDIES BE ABOUT?

GOOD QUESTION, HANNAH. A RESEARCHER MIGHT STUDY WHY PEOPLE GET A CERTAIN DISEASE OR HOW BEST TO TREAT ONE.

SOME OF THESE SAMPLES MIGHT BE USED TO LEARN WHY PEOPLE HAVE PEANUT ALLERGIES.

OR THEIR STUDY MAY BE ABOUT SOMETHING TOTALLY DIFFERENT.

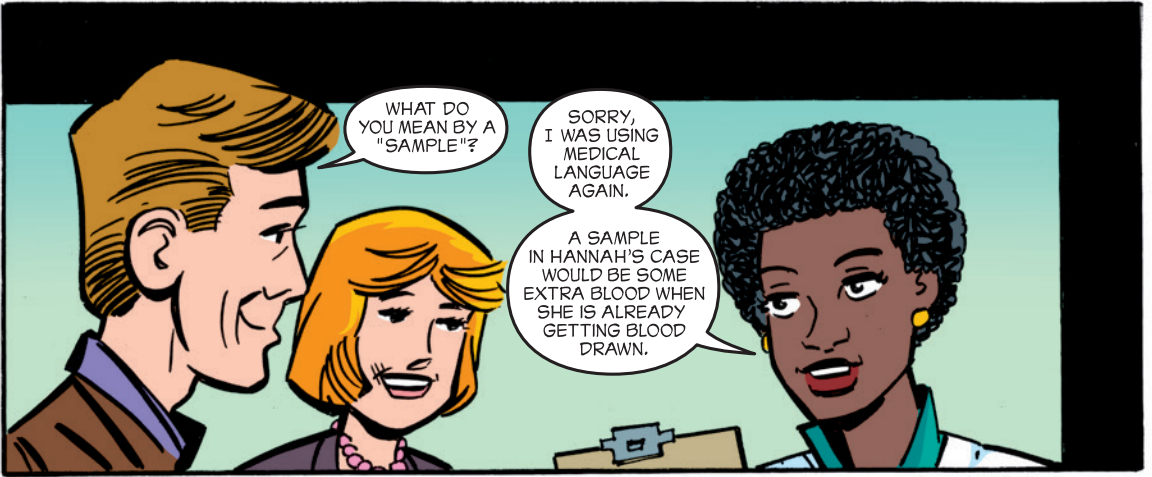


WHAT INFORMATION AND SAMPLES DO THEY COLLECT?

THAT DEPENDS ON THE BIOBANK. SOME BIOBANKS JUST KEEP SAMPLES, WHILE OTHERS HAVE ADDITIONAL INFORMATION FROM MEDICAL RECORDS. OF COURSE, NEITHER THE PATIENT'S NAME NOR ANY INFORMATION TO IDENTIFY THEM IS ATTACHED TO IT.

WHAT THE SCIENTISTS ASK FOR DEPENDS ON THEIR STUDY. SOME RESEARCHERS FROM THIS HOSPITAL GET TO LOOK AT SOME GENERAL PATIENT INFORMATION, LIKE AGE, GENDER, DIAGNOSIS, OR TREATMENTS TRIED.

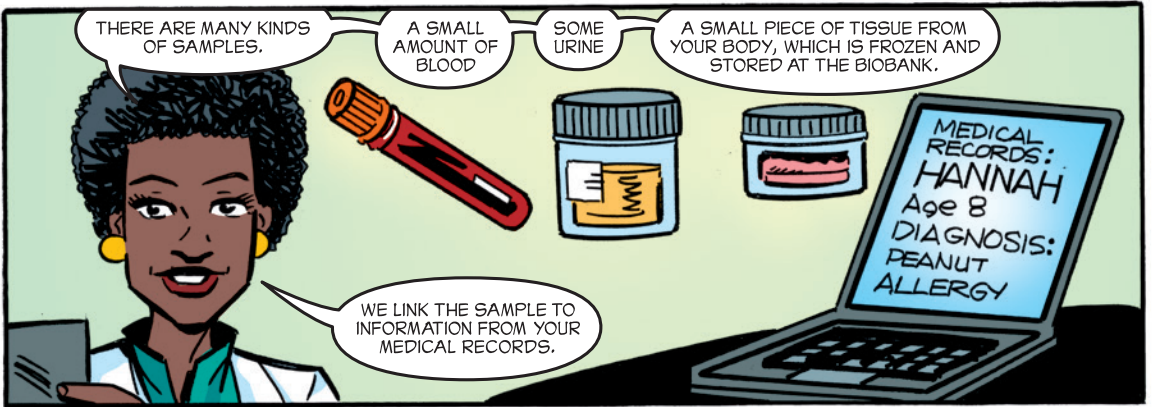
A SCIENTIST FROM ANOTHER HOSPITAL MIGHT ONLY GET THE DATA FROM THE SAMPLE BUT NOT THE INFORMATION FROM MEDICAL RECORDS.



WHAT DO YOU MEAN BY A "SAMPLE"?

SORRY, I WAS USING MEDICAL LANGUAGE AGAIN.

A SAMPLE IN HANNAH'S CASE WOULD BE SOME EXTRA BLOOD WHEN SHE IS ALREADY GETTING BLOOD DRAWN.



THERE ARE MANY KINDS OF SAMPLES.

A SMALL AMOUNT OF BLOOD

SOME URINE

A SMALL PIECE OF TISSUE FROM YOUR BODY, WHICH IS FROZEN AND STORED AT THE BIOBANK.

WE LINK THE SAMPLE TO INFORMATION FROM YOUR MEDICAL RECORDS.

MEDICAL RECORDS:
HANNAH
Age 8
DIAGNOSIS:
PEANUT ALLERGY

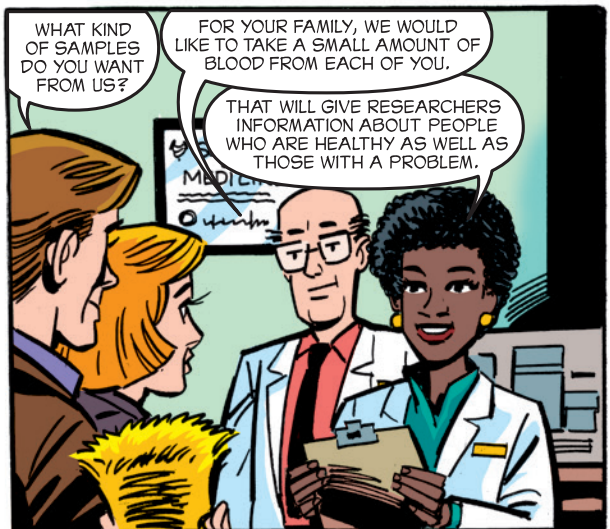


WOULD WE HAVE TO HAVE AN OPERATION SO YOU CAN TAKE A PIECE OF TISSUE FROM OUR BODY?

NO, GEORGE. WE ONLY ASK PERMISSION FOR A TISSUE SAMPLE IF THE PERSON IS ALREADY HAVING AN OPERATION. THEN WE MIGHT ASK TO KEEP SOME OF THE EXTRA TISSUE FOR RESEARCH.



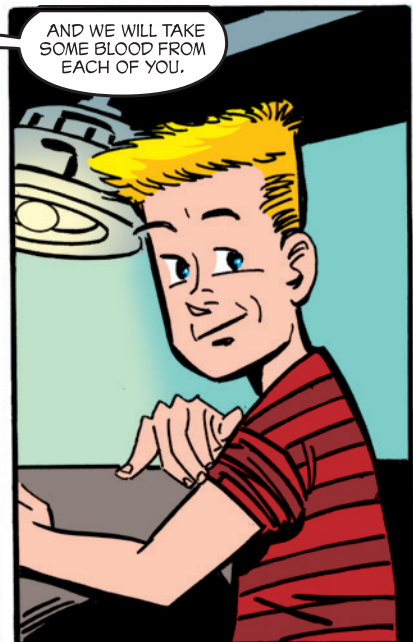
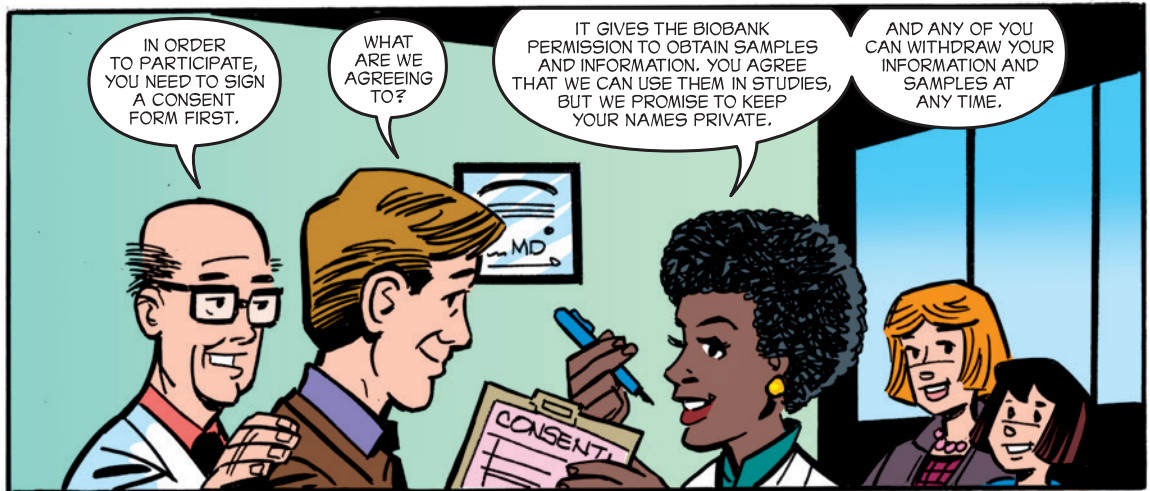
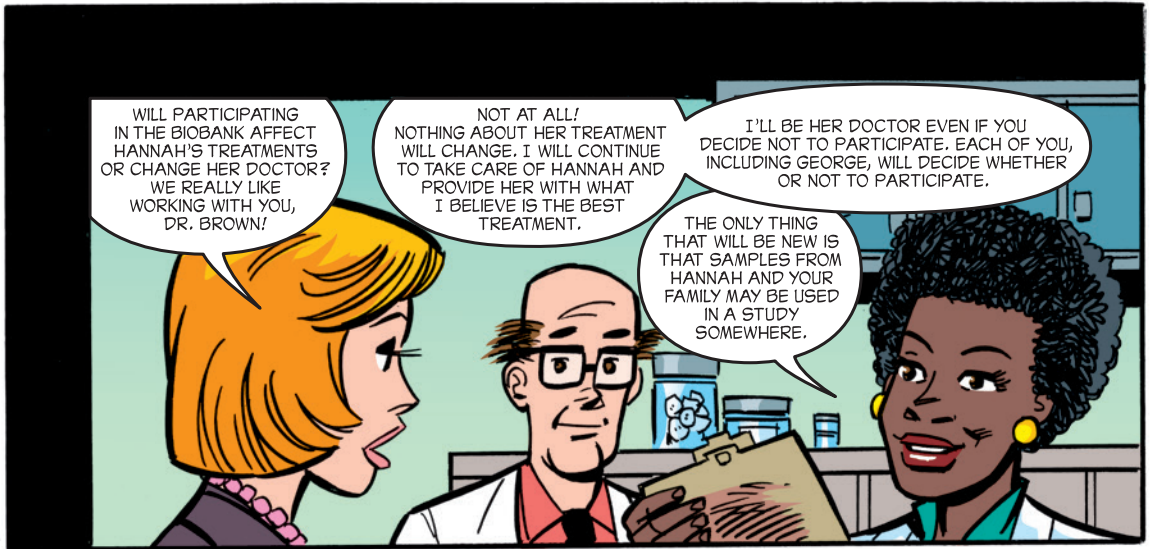
SINCE MANY RESEARCHERS NEED INFORMATION ABOUT PEOPLE WHO ARE HEALTHY AS WELL AS THOSE WITH A PROBLEM, WE ALSO WANT INFORMATION ABOUT THE OTHER PEOPLE IN YOUR FAMILY.

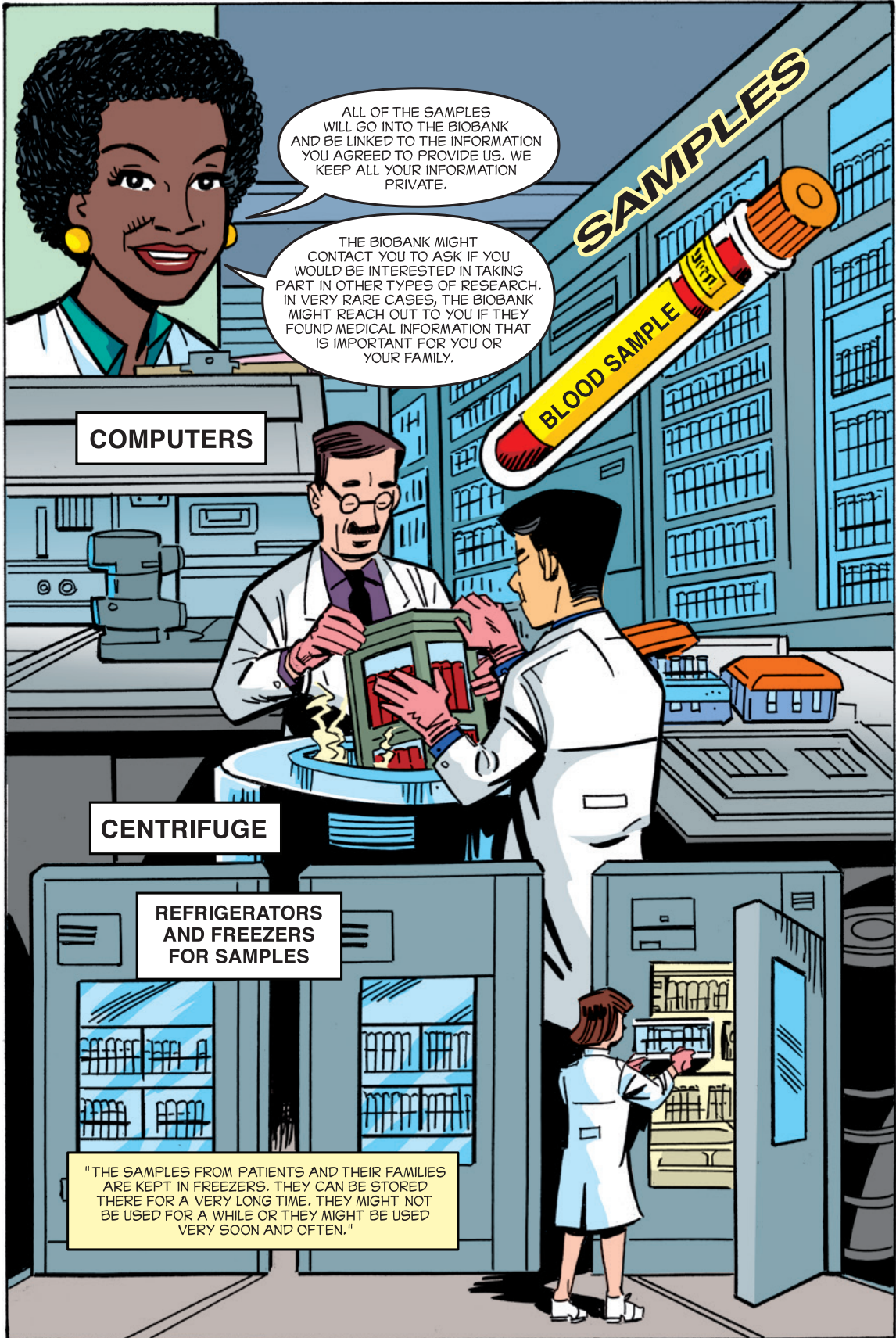


WHAT KIND OF SAMPLES DO YOU WANT FROM US?

FOR YOUR FAMILY, WE WOULD LIKE TO TAKE A SMALL AMOUNT OF BLOOD FROM EACH OF YOU.

THAT WILL GIVE RESEARCHERS INFORMATION ABOUT PEOPLE WHO ARE HEALTHY AS WELL AS THOSE WITH A PROBLEM.





ALL OF THE SAMPLES WILL GO INTO THE BIOBANK AND BE LINKED TO THE INFORMATION YOU AGREED TO PROVIDE US. WE KEEP ALL YOUR INFORMATION PRIVATE.

THE BIOBANK MIGHT CONTACT YOU TO ASK IF YOU WOULD BE INTERESTED IN TAKING PART IN OTHER TYPES OF RESEARCH. IN VERY RARE CASES, THE BIOBANK MIGHT REACH OUT TO YOU IF THEY FOUND MEDICAL INFORMATION THAT IS IMPORTANT FOR YOU OR YOUR FAMILY.

COMPUTERS

CENTRIFUGE

REFRIGERATORS AND FREEZERS FOR SAMPLES

"THE SAMPLES FROM PATIENTS AND THEIR FAMILIES ARE KEPT IN FREEZERS. THEY CAN BE STORED THERE FOR A VERY LONG TIME. THEY MIGHT NOT BE USED FOR A WHILE OR THEY MIGHT BE USED VERY SOON AND OFTEN."

SAMPLES
BLOOD SAMPLE

ONE THING BIOBANKS AND RESEARCHERS DO IS ANALYZE YOUR BLOOD.

YOUR BODY, INCLUDING YOUR BLOOD IS MADE UP OF CELLS.

CELL NUCLEUS

IN THE CENTER OF THE CELL IS THE NUCLEUS AND IN THAT IS THE DNA.

DNA

DNA IS UNIQUE TO EACH PERSON. YOU GET SOME OF IT FROM EACH PARENT.

SOMETIMES STUDYING DNA CAN HELP EXPLAIN WHY A PERSON GETS A DISEASE OR A SPECIFIC ILLNESS, SO WE LOOK INSIDE YOUR CELLS.

DR SMITH

HOW DO YOU DECIDE WHO GETS THE SAMPLES AND WHO DOESN'T? WHO MAKES THAT DECISION?

WE ARE VERY CAREFUL ABOUT WHO GETS ANYTHING FROM OUR BIOBANK. WE GET MANY REQUESTS FROM SCIENTISTS FOR SAMPLES AND INFORMATION.

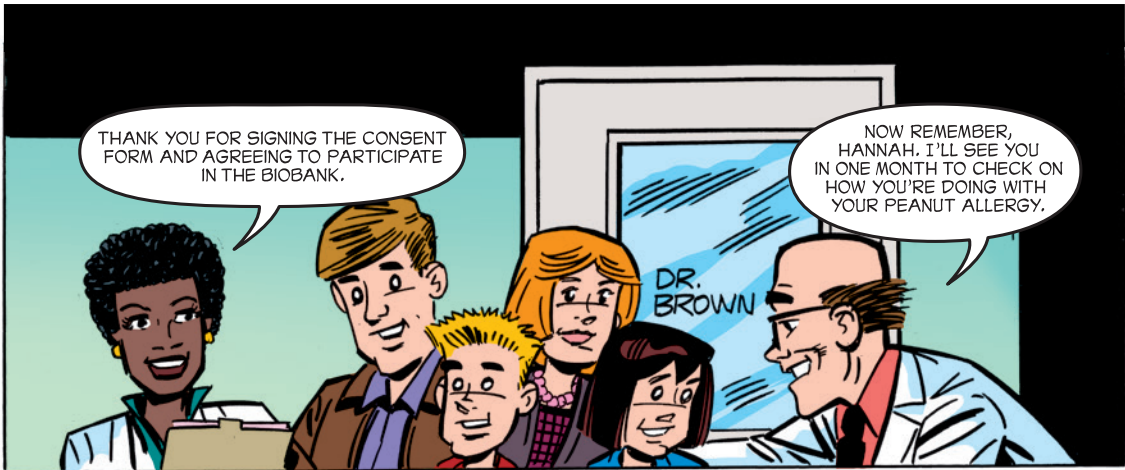
I CAREFULLY EVALUATE THE REQUESTS WITH THE HELP OF OTHER PHYSICIANS AND SCIENTISTS. WE MAKE SURE THAT THIS RESEARCH HAS A GOOD PURPOSE AND IS WELL DONE.

SO WHAT HAPPENS TO THE SAMPLES YOU COLLECT FROM US?

Biobank X

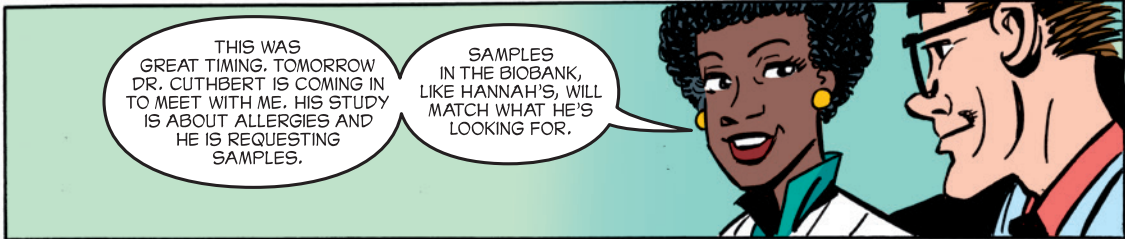
"ONCE WE HAVE YOUR SAMPLES, THE BIOBANK STORES THEM UNTIL A RESEARCHER NEEDS THEM FOR A RESEARCH STUDY. HE OR SHE MAY ASK FOR SAMPLES FROM PEOPLE WITH ALLERGIES, OR PEOPLE OF A CERTAIN AGE, OR MAYBE PEOPLE WITHOUT ANY ALLERGIES AT ALL. IF YOUR SAMPLE MEETS THE CRITERIA FOR THAT STUDY, WE CAN SHARE IT."

"YOUR SAMPLE IS IDENTIFIED ONLY BY A CODE, NOT YOUR NAME. IT MIGHT BE SENT TO ONE SCIENTIST OR TO MANY DIFFERENT RESEARCH SCIENTISTS DOING DIFFERENT KINDS OF STUDIES. IT MIGHT BE USED IN OUR HOSPITAL OR SENT SOMEWHERE ELSE."



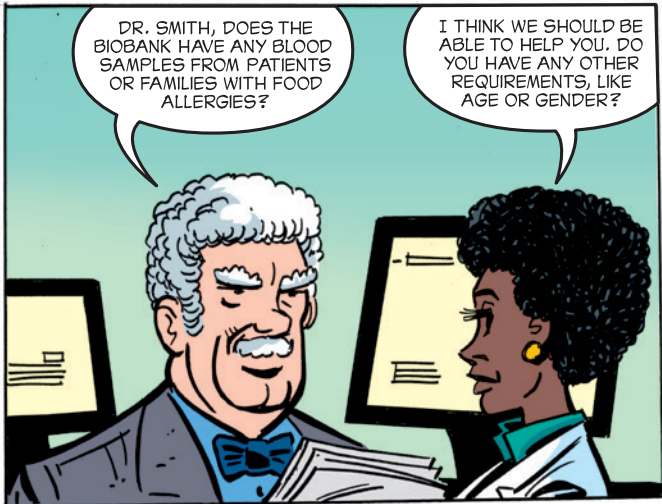
THANK YOU FOR SIGNING THE CONSENT FORM AND AGREEING TO PARTICIPATE IN THE BIOBANK.

NOW REMEMBER, HANNAH. I'LL SEE YOU IN ONE MONTH TO CHECK ON HOW YOU'RE DOING WITH YOUR PEANUT ALLERGY.



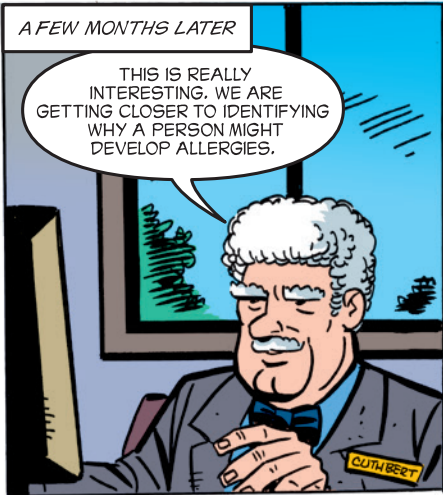
THIS WAS GREAT TIMING. TOMORROW DR. CUTHBERT IS COMING IN TO MEET WITH ME. HIS STUDY IS ABOUT ALLERGIES AND HE IS REQUESTING SAMPLES.

SAMPLES IN THE BIOBANK, LIKE HANNAH'S, WILL MATCH WHAT HE'S LOOKING FOR.



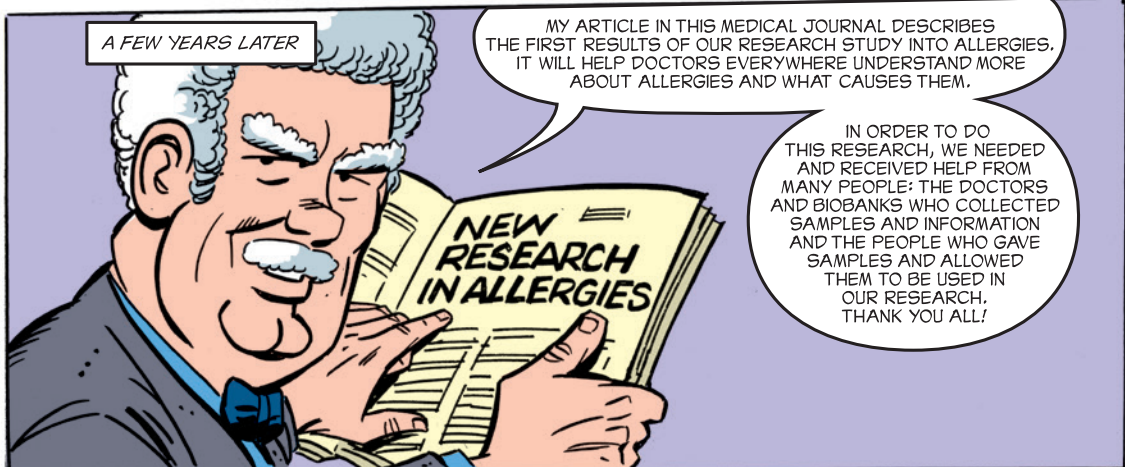
DR. SMITH, DOES THE BIOBANK HAVE ANY BLOOD SAMPLES FROM PATIENTS OR FAMILIES WITH FOOD ALLERGIES?

I THINK WE SHOULD BE ABLE TO HELP YOU. DO YOU HAVE ANY OTHER REQUIREMENTS, LIKE AGE OR GENDER?



A FEW MONTHS LATER

THIS IS REALLY INTERESTING. WE ARE GETTING CLOSER TO IDENTIFYING WHY A PERSON MIGHT DEVELOP ALLERGIES.



A FEW YEARS LATER

MY ARTICLE IN THIS MEDICAL JOURNAL DESCRIBES THE FIRST RESULTS OF OUR RESEARCH STUDY INTO ALLERGIES. IT WILL HELP DOCTORS EVERYWHERE UNDERSTAND MORE ABOUT ALLERGIES AND WHAT CAUSES THEM.

IN ORDER TO DO THIS RESEARCH, WE RECEIVED HELP FROM MANY PEOPLE: THE DOCTORS AND BIOBANKS WHO COLLECTED SAMPLES AND INFORMATION AND THE PEOPLE WHO GAVE SAMPLES AND ALLOWED THEM TO BE USED IN OUR RESEARCH. THANK YOU ALL!

REMEMBER...

- **Research is how we learn** about the causes and treatment of illnesses.
- Researchers need both information and biological samples to do research. These are stored in a **Biobank**. You may be asked to give either information or samples or both to a **Biobank**.
- We collect **medical information** from hospital records or by asking you questions.
- The samples we collect may include **blood, urine, spit** or **tissue** from your body. Most times we collect these when you are having medical tests that require these samples.
- Information and samples in the Biobank may be **shared** with clinicians and scientists who do research.
- **If you decide not** to give anything to the Biobank, you will still get medical care and it will not affect your care in any way. Participation is entirely voluntary.
- **Make sure you understand** what you will need to do for the Biobank. For example, you might want to know how many times you will be asked to give information or samples or whether researchers will ever contact you in the future. **Ask any questions you have.**
- Your opinion is important. **Talk to your parents** about the research before you decide if you want to participate or not.
- **You can stop** participating in the Biobank at any time. Just let your parents and the Biobank know.



**HARVARD
CATALYST**

THE HARVARD CLINICAL
AND TRANSLATIONAL
SCIENCE CENTER



**Boston
Children's
Hospital**

Where the world comes for answers