FAP & Me

A Kid's Guide to
Familial **A**denomatous **P**olyposis

A NOTE TO PARENTS:

Welcome to "FAP & Me!" This booklet was written to reinforce the information about FAP that you, your doctors, and your genetic counselor have given your child. FAP & Me is useful in various ways, depending on the age of the child. Each child and family is different, and FAP & Me may have information that you have not shared with your child yet. Please review FAP & Me to see whether the information is right for your child at this time. Your child may like reading FAP & Me with you, an older sibling, or another adult so that he or she can ask questions and have you explain things. We hope that FAP & Me is helpful!

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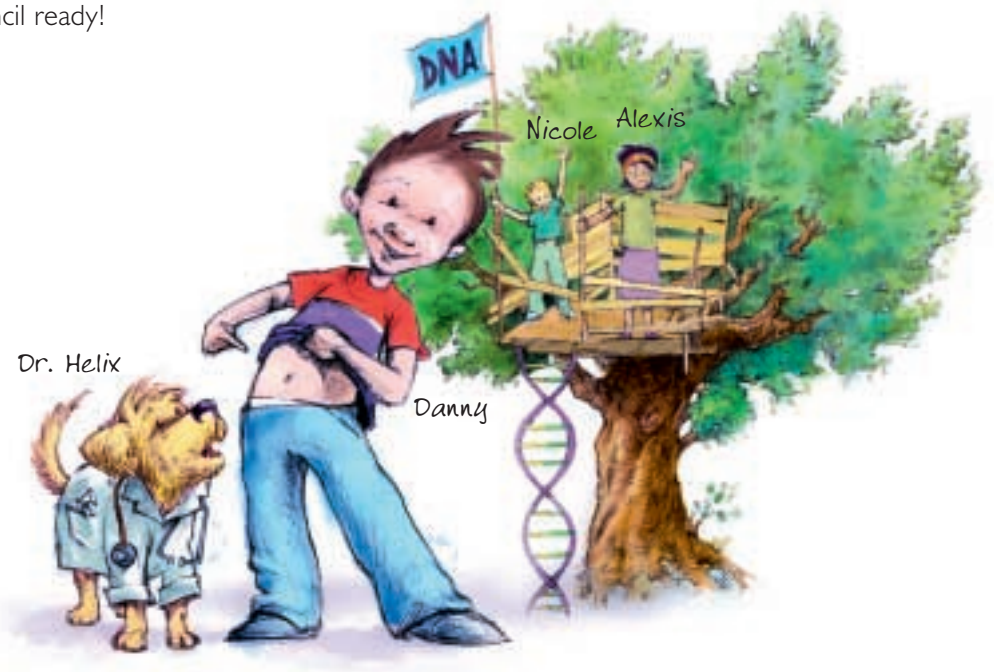
WOULD YOU LIKE TO LEARN MORE ABOUT FAP?

Yes? Then meet Dr. Helix. Dr. Helix knows more about FAP than just about any other dog on the planet. He also knows a lot about the digestive system. Dr. Helix and his friends Danny, Nicole and Alexis have a club called the DNA Club. The DNA Club helps kids learn about FAP. You see, Danny, Nicole and Alexis all have FAP. You can join the DNA Club on a learning adventure by reading this booklet.

The booklet is for people who have FAP or who may have FAP because it is in their family. You may want to read it with your parents or another adult. This booklet has a lot of information about FAP. It explains big words and answers questions that kids often ask when they first learn about FAP. New words are in **bold** and are listed at the end of booklet. Dr. Helix and the DNA Club have included some fun activities in the booklet, so get your pencil ready!

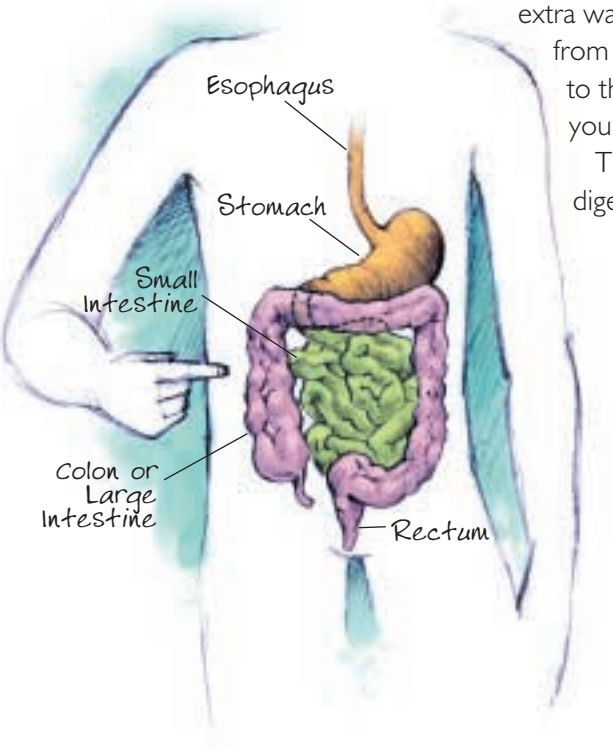


WHAT IS FAP?

FAP stands for **Familial Adenomatous Polyposis**. That is a lot to say, so most people just call it FAP. Another name for FAP is **Gardner syndrome**. They are different names for the same condition.

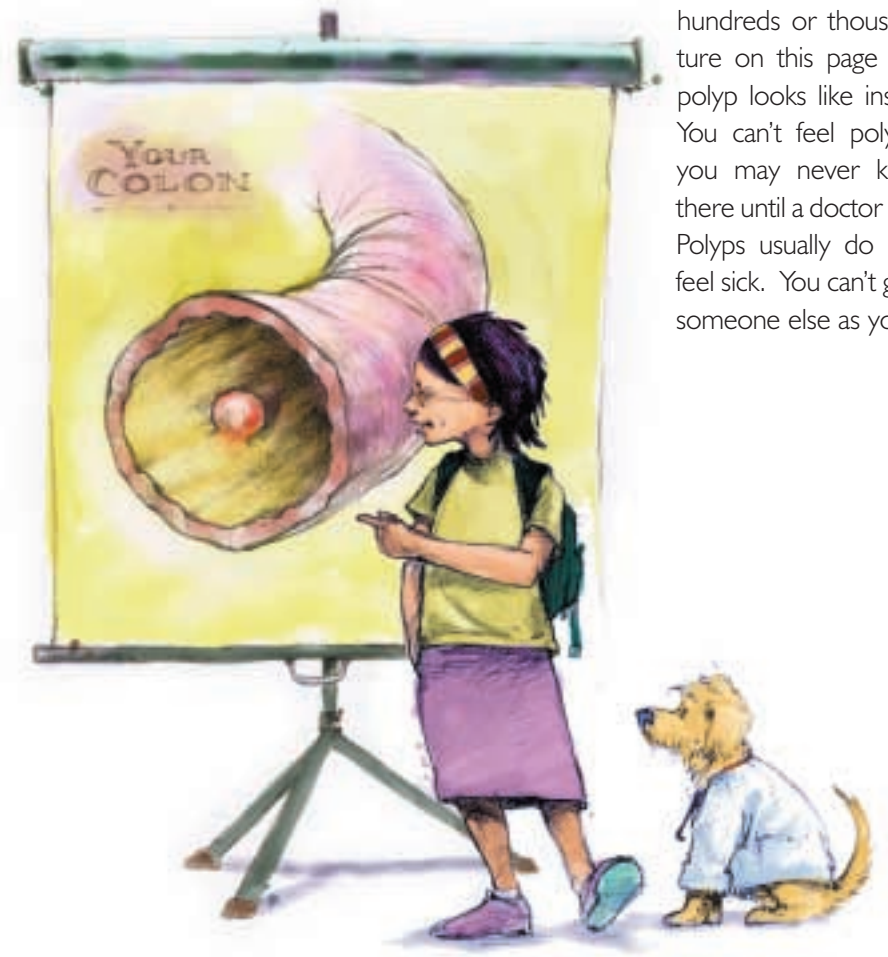
FAP affects many parts of the body, but mostly the digestive system. This system breaks down food to give you energy and makes waste. When you eat, the food that you swallow goes down a tube called the **esophagus** and into your stomach. It goes from your stomach to your **small intestine**, and enters your **colon**. The job of the colon is to remove extra water or fluid from the waste. The waste from your body then moves from the colon to the **rectum**, and is pushed out when you have a bowel movement (go poop).

■ Did you know that there are more than 100 different words for poop in many languages around the world? Which word do you use in your family?



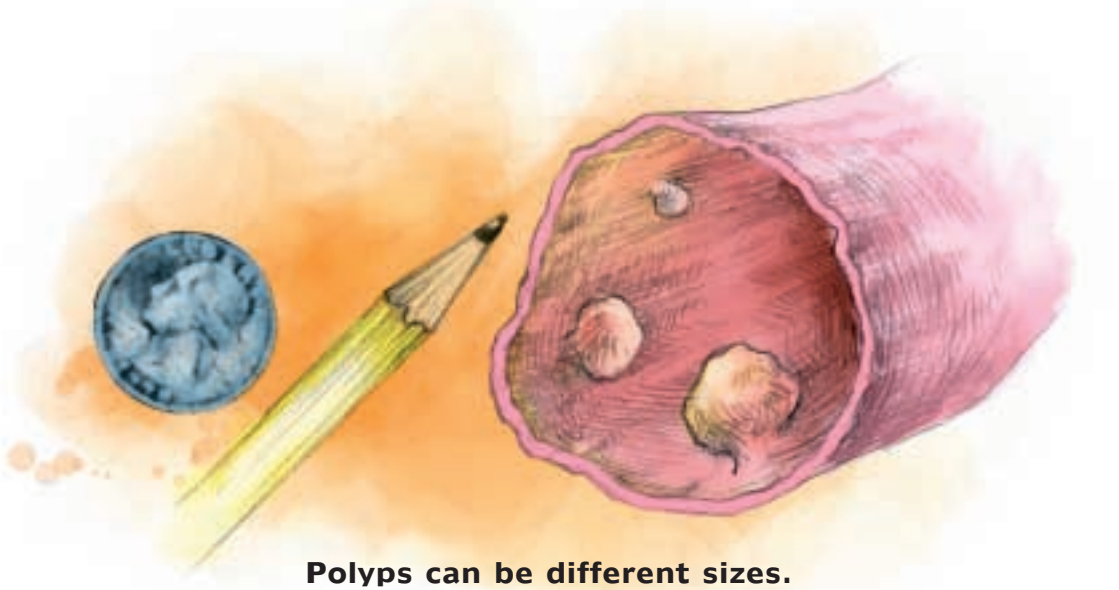
This drawing shows all of the parts of the digestive system. See the colon?

Mushroom-shaped bumps can grow inside the colon and rectum. These are called **polyps**. It is not unusual for children and adults to get one or two colon polyps that are harmless. But people with FAP get many polyps much earlier. Many kids with FAP start to get polyps when they are 10, 11 or 12 years old. Some start earlier, some start later. People with FAP get lots of polyps — often hundreds or thousands. The picture on this page shows what a polyp looks like inside the colon. You can't feel polyps grow, and you may never know they are there until a doctor looks for them. Polyps usually do not make you feel sick. You can't get polyps from someone else as you can a cold.



Colon polyps are not **cancer**, but they must be removed because some of them (the ones called **adenomas**) can turn into cancer. Cancer is what happens when **cells** in a part of the body grow out of control. The cells change and do not work right. They can crowd the normal cells and not let them do their usual jobs in the body.

People with FAP sometimes get polyps in other parts of their digestive system, like the stomach and small intestine. People with FAP can also get small lumps and bumps on their bones or skin. These lumps and bumps usually do not cause any health problems, are not cancer and can be removed. Some people with FAP also have extra or missing teeth. Most of the time people — even doctors — can't tell who has FAP just by looking at them.



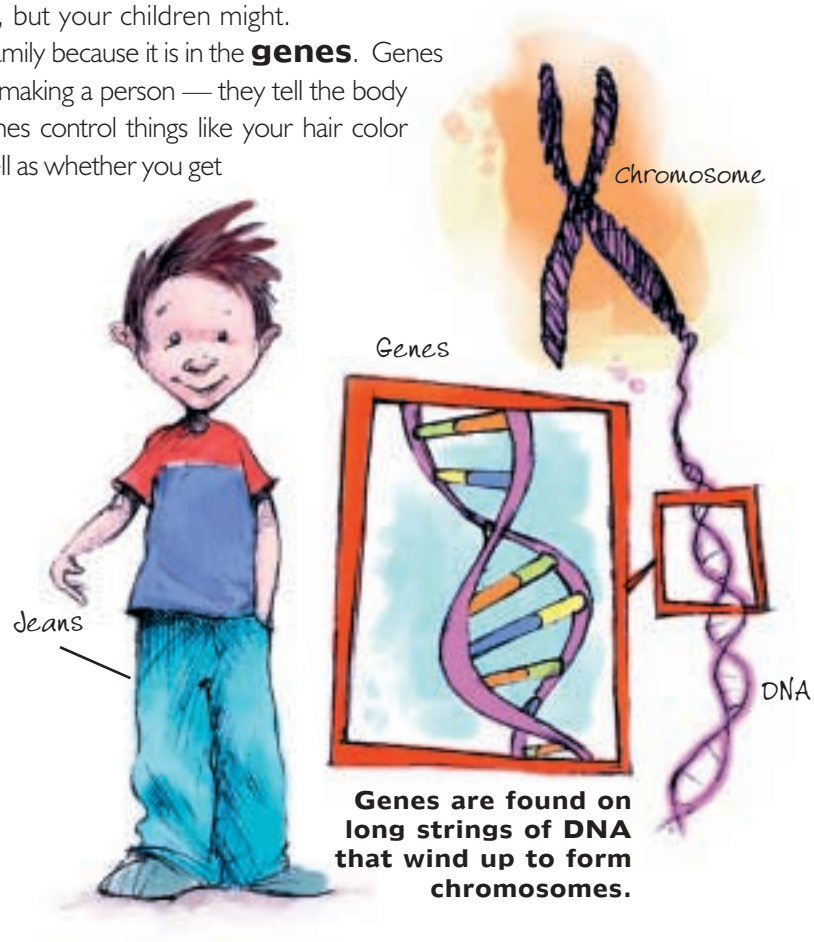
Polyps can be different sizes.

DOES FAP RUN IN FAMILIES?

In some families, health problems are passed from grandparents to parents to children. This happens before you are born. This is called an **inherited** condition. Sometimes we say that an inherited condition "runs in the family."

FAP runs in families, so most kids with FAP have a parent with FAP. There may also be other people in your family who have FAP like your brothers or sisters, a grandparent, aunts, uncles or cousins. However, sometimes a person with FAP is the first one in the family to have it. Once someone has FAP, it can run in the family after that. If you are the first person in your family with FAP, your parents and brothers and sisters do not have it, but your children might.

FAP can run in a family because it is in the **genes**. Genes are like a recipe for making a person — they tell the body how to work. Genes control things like your hair color and eye color, as well as whether you get some diseases.

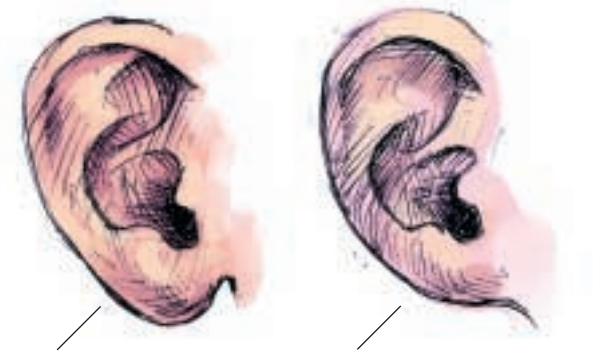


Genes are found on long strings of DNA that wind up to form chromosomes.

People get their genes from their parents. Half of your genes came from your mom and half came from your dad. Someone may have told you that certain things about you (like your smile or the shape of your nose) make you look like one of your parents. Here are some funny features that can run in families.

Tongue rolling: Some people can roll up the edges of their tongue, while other can't. The ability to roll your tongue is inherited.

Earlobe shapes can run in families too.



What other parts of you came from your mom and your dad? Write them down below.

Mom: _____ **Dad:** _____

Changes in genes — also called **mutations** — can cause health problems. People with FAP are born with a mutation that makes one gene stop working the way it should. That's what causes FAP.

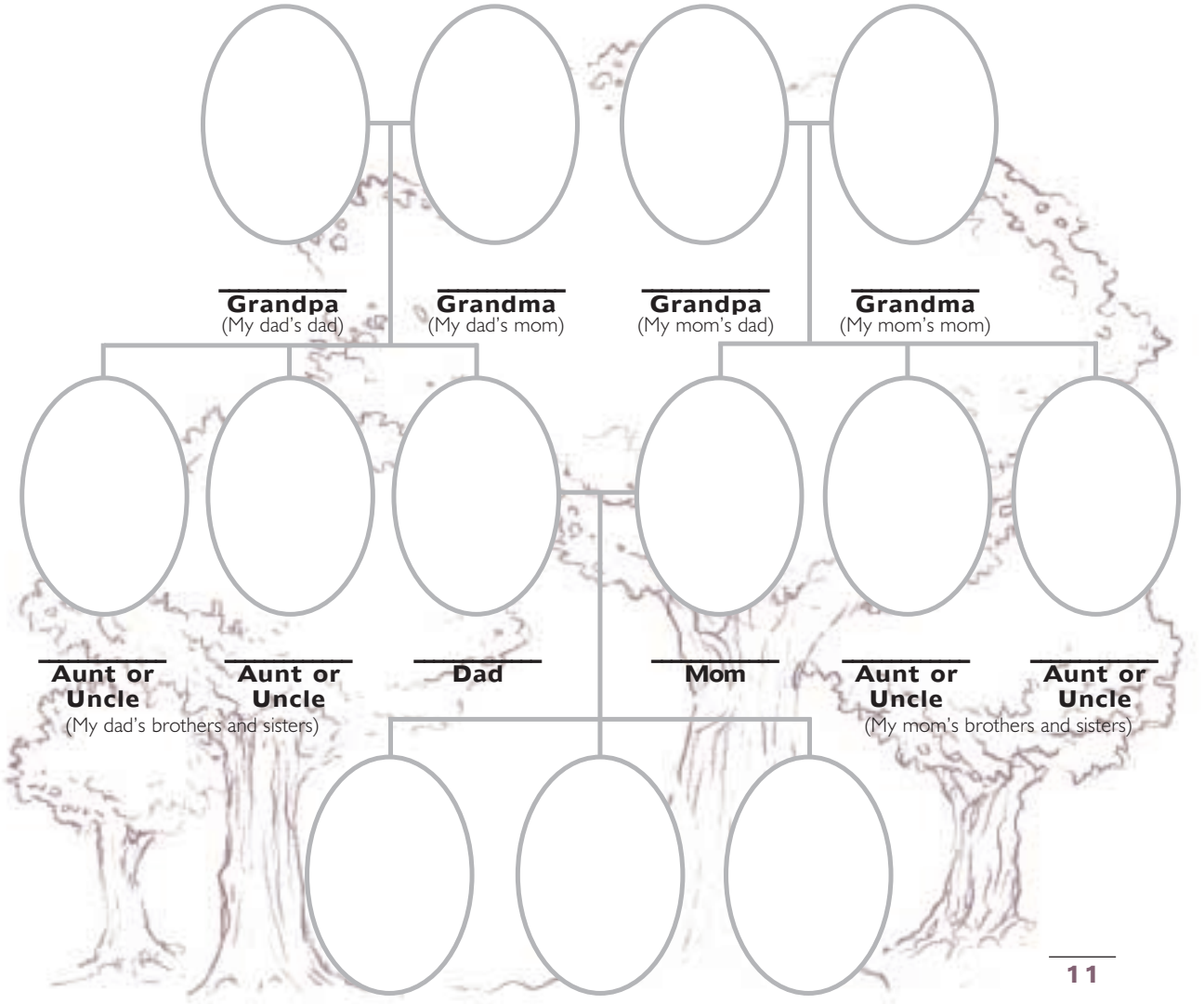
If one of your parents has FAP, you have a chance of getting it too. Your chance of having FAP is the same as your chance of not having FAP. In math terms, this is called a 50% chance, or 1 chance in 2. This is like the chance of a coin landing heads-up when you flip it. This chance is the same for every kid in the family. In some families, all the children will inherit FAP. In others, none of the kids will get FAP. Many times, some of the kids will have FAP and some won't. Once in a while, more than one kid in a family has FAP even when the parents do not. If your family is like this, a genetic counselor can help explain why. Whether or not you have FAP, you still share many other genes in common with your family members.

The drawing on this page shows a family tree. The people shown with a purple background have FAP. You can see that the grandfather had FAP, and that only one of his daughters got it. Then, two of her three kids got FAP.

MY FAMILY TREE

Now it's your turn to draw your family tree!

Draw pictures of your family members and put their names underneath. Use a different color of background for those family members who have FAP. If you would like to add more family members, make a family tree on a separate piece of paper and find out where FAP came from in your family and who has it now.



HOW DO I KNOW IF I HAVE FAP?

If you already have polyps, then you already know you have FAP. If you don't have polyps yet, there are two ways to find out if you have FAP. You can have a genetic test, or you can wait to see if polyps grow.

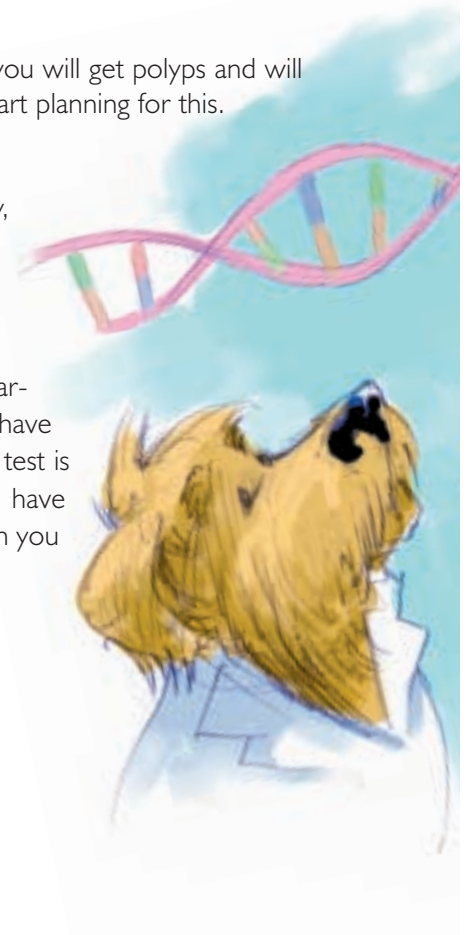
In most families, a genetic test can tell whether a kid has FAP even before they get polyps. A genetic test looks for a change in the gene for FAP. There are reasons you might have the test and reasons you might not. Each family makes its own choice about genetic testing.

If you have the genetic test, you will find out for sure whether or not you have FAP. Many kids and parents like this better than waiting and wondering.

- You may find out that you have FAP. Then you know you will get polyps and will need check-ups to look for polyps every year. You can start planning for this.

- You may find out that you do not have FAP at all. If you do not have the gene change that causes FAP in your family, you will never get FAP. You can wait until you are much older (usually 40 or 50) to be checked for polyps, like other people without FAP.

In some families, genetic testing is not useful. And some parents and kids would rather wait and see if polyps grow than have a genetic test. If you do not have the genetic test, or if the test is not useful for the genetic change in your family, you will have check-ups every year to look for polyps. If polyps grow, then you know you have FAP.



HOW IS GENETIC TESTING DONE?

First, you need to find out if genetic testing will be useful for you. Usually, someone else in your family who already has FAP has to have the test first. If their genetic test finds a change in the gene for FAP, then your test will look for the same genetic change. Not all genetic changes can be found. If the change can't be found in a family member who already has FAP, then it wouldn't show up in you either, even if you really did have FAP. In this case, the test is not useful. It is a good idea to talk about this with your doctor or **genetic counselor**.

The genetic test is usually a blood test. If you have the genetic test, you will have a little blood drawn. Some people are scared of this because it is done with a needle, but it doesn't hurt that much. Most people say it feels like a pinch on the arm. You may have had a blood test before and know exactly what it feels like. It may take several weeks to get the answer from the genetic test.

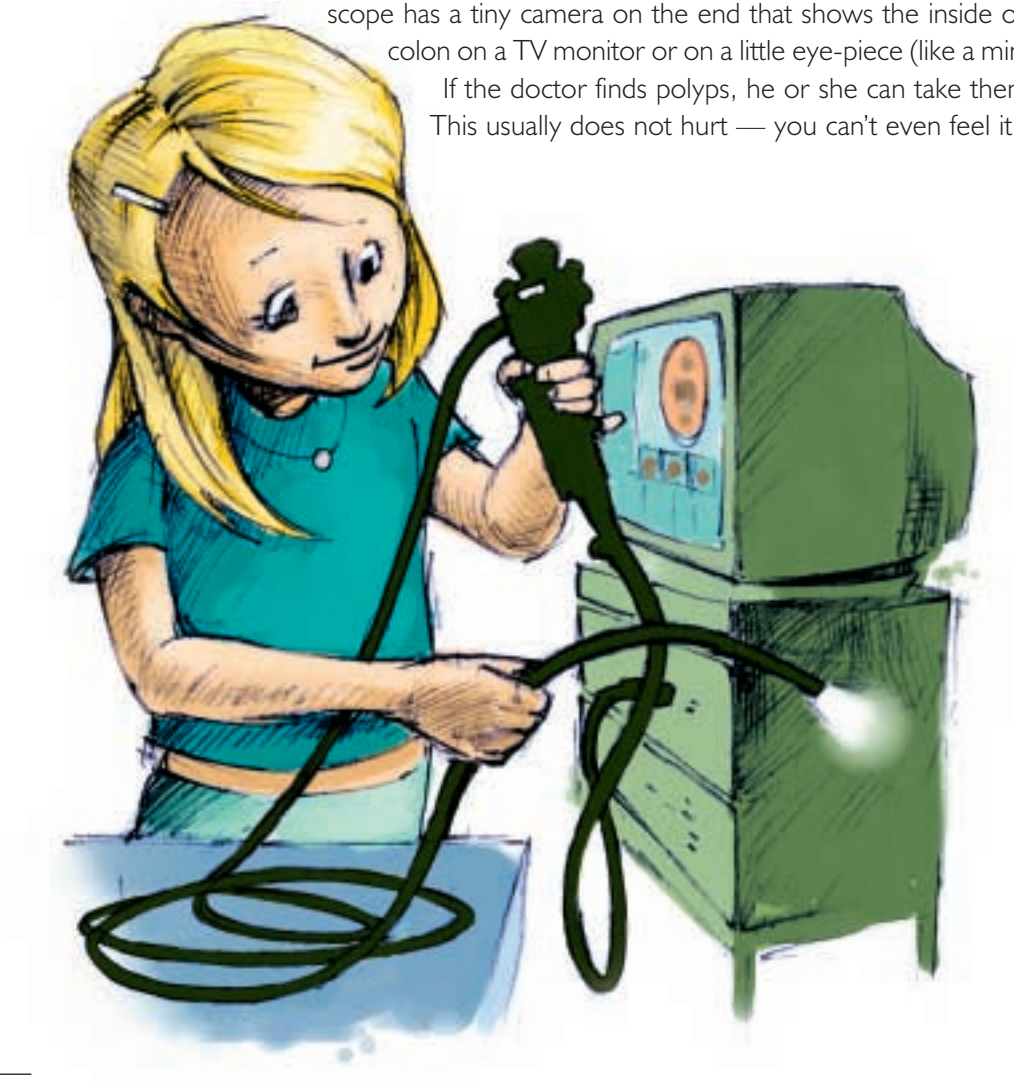
Has anyone in your family had a genetic test?

How do you feel about having a genetic test?

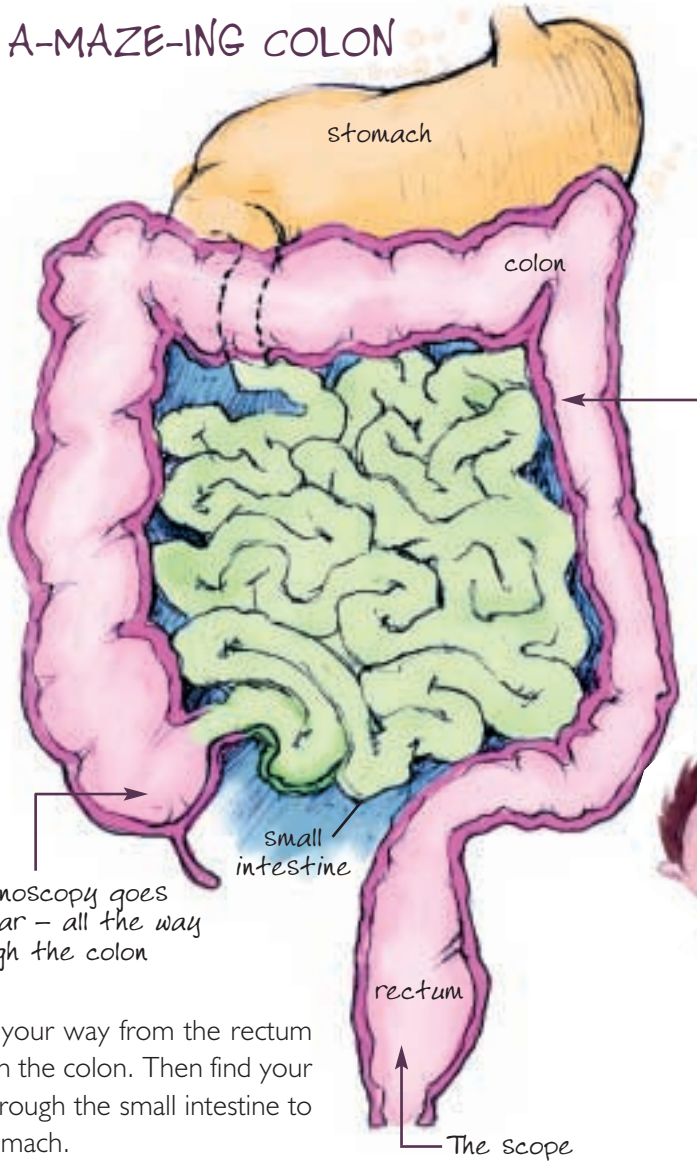
If you want to, you can use this space to write down what you think about having a genetic test. If you already had the genetic test, what do you remember about it?

HOW DO DOCTORS CHECK FOR POLYPS?

Doctors check for polyps by using a scope. A scope is a thin flexible tube with a light on the end. The scope goes into your colon through your rectum. Depending on how far the scope goes, this test may be called a **sigmoidoscopy** or a **colonoscopy**. The scope has a tiny camera on the end that shows the inside of your colon on a TV monitor or on a little eye-piece (like a mini TV). If the doctor finds polyps, he or she can take them out. This usually does not hurt — you can't even feel it.



THE A-MAZE-ING COLON



Find your way from the rectum through the colon. Then find your way through the small intestine to the stomach.

Colon Quote

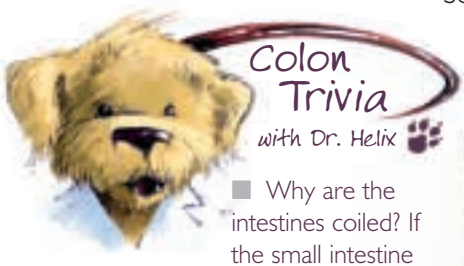
"I don't like getting my colon checked, but I know that it keeps me healthy — and the doctors and nurses are nice."

Most kids with FAP have to be checked for polyps once a year. Being checked for polyps may not seem like fun, but it is really important for your health. Being checked for polyps usually doesn't hurt.

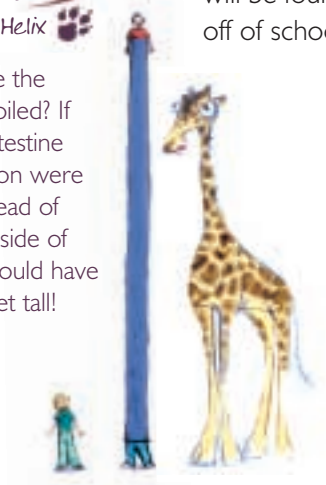
There are certain things to expect about a colon check-up. For the scope, your colon and rectum need to be empty (no poop). How you get ready for the scope depends upon whether you have a sigmoidoscopy or a colonoscopy. You may have to do some of the following things:

- Before you are to be checked, you may not be able to eat.
- You may have to take some medicine. The medicine makes you poop a lot and cleans out your colon.
- You or the doctor may wash out the colon and rectum by squirting some liquid into your rectum (this is called an enema).
- You may be given some medicine to make you sleepy during the scope.
- You may miss school the day of your colon check.

Sometimes when you go for scopes you may worry — many people do. You may worry that the test will hurt, even if it usually doesn't. You may worry that polyps will be found. Or, you may not mind having a day off of school — even if it means getting scoped!



- Why are the intestines coiled? If the small intestine and the colon were straight instead of coiled up inside of you, you would have to be 25 feet tall!



WHAT IF I HAVE FAP?

You may already know that you have FAP. You may have found out by having the genetic test, or you might have signs of FAP, like polyps in your colon.

You may not like having FAP. You may know that other people in your family with FAP had surgery or have health problems. People with FAP do have certain health problems, but FAP can be different in everyone who has it — even in members of the same family. You may not have the same health problems that other people in the family have had. It is important to remember that lots of people with FAP live long, healthy lives.

These are important ways to stay healthy with FAP.

- Healthy habits: Help your body stay healthy by eating good foods and exercising.
- Scopes! Make sure to have scopes of the colon every year, or more often if your doctor tells you to.
- Surgery: At some point you will have **surgery** to take out your colon if you have FAP.
- More scopes! After your surgery, you will still have scopes to check for polyps in the rest of the digestive tract (the stomach, small intestine, and rectum).
- Medicine: Your doctor may give you medicine to take because you have FAP. It is important to follow the directions for taking the medicine.

WHAT IF I NEED SURGERY?

Colon Trivia
with Dr. Helix

■ Did you know that a person can live a long, happy, healthy life without a colon?

Most people who have FAP start to get polyps sometime between the ages of 10 and 18. At first, there may be just a few polyps. After a while, when there are too many polyps, you will need to have surgery to remove your colon. Otherwise, some polyps will grow into cancer. Without a colon, you will have a much lower chance of getting cancer. There are different types of surgeries. Your doctor and your parents can tell you more about the kind of surgery you might have, when you will need the surgery and what you can expect during and after.

Colon Quote

"I don't worry about getting colon cancer because I'll have my colon removed before that can happen."

WHAT SIGNS SHOULD I WATCH FOR?

There are some signs that might be the first clues that you have started to get polyps. Keep in mind that having one of these signs does not mean for sure that you have polyps or cancer. Be sure to tell your parents so that they can help you find out what's happening.

Here is a list of signs to watch for:

- Bright red or dark red blood when you have a bowel movement (tiny spots or lots).
- Stool (poop) that is thin like a pencil most of the time.
- Cramps or sharp pains in your stomach that happen a lot.
- Diarrhea (loose, watery stool) or constipation (when you don't go as often as usual or it is hard to go) that happens a lot.
- Feeling bloated (your belly feels all stretched out, too full, or blown up like a balloon).
- Losing weight.
- Feeling like you don't have any energy.

Kids with FAP and kids who may have FAP will need scopes even when there aren't any of these signs. Polyps often do not cause any signs at all. Sometimes there can be more than one sign.

Signs are like clues. You won't know what they mean until your doctor checks. You should tell your parents and your doctor, even if you think:

- It is embarrassing to talk about.
- I don't know if this sign is important.
- Maybe I could wait—maybe it will go away.
- I don't want anyone to worry about me.
- If I tell about the signs I might have to get another scope.
- I wish I could ignore these signs because I don't want to have FAP.

Colon Quote

"Signs of FAP are important to my doctor, and she can tell me what they might mean."

WORD SEARCH!

All of the words listed below can be found in the puzzle.

Words can go across, down, diagonally, forward or backward. Circle all of the words that you find.

K C H U B D C E L L S P Z F G
X I O M S I E H D Q K X T A N
K K A L K Y Q T G H S P R J O
H V L G O V D Y I P E D A N I
R O L E S N U O C R N H O F T
P D O Z T M P Z L E E I J F A
F E E L I N G S R A T H M Y R
H G E E P R D S L A S F N L E
L O A F O Z Y T T C U D B I P
R C S T Y N H U O U R Q A M O
G E C P D Y M P V A G T T A L
K O C R I G E S D N E I R F Y
D I O N L T K H F Z R R E R P
M M P K A N A S T Q Y E N E G
E X I A W C L L K V H S L T Z

cells
cancer
colon
counselor
doctor
family
FAP
feelings
friends
Gardner syndrome
gene
healthy
hospital
inherited
mutation
operation
polyp
scope
surgery

HOW DOES FAP AFFECT MY LIFE?

Sometimes, kids worry that other people will treat them differently if they have FAP. Remember, your friends (and others) will not know that you have FAP unless you tell them. Kids who have FAP do not look different. It is possible that you may have met someone who has FAP and you did not know it. For many kids, learning they have FAP does not change their life much. Every kid is different and can have different feelings about having FAP. No matter how you feel – IT IS OKAY. You may have different feelings about having FAP at different times in your life.

Sometimes you may feel:

- Like you are different than other kids.
- That FAP is NO BIG DEAL.
- Tired of talking about it.
- That having FAP is NOT FAIR!
- Lonely that you have FAP and others don't.
- Confused - "What are they talking about?".
- Sad.
- Worried that having FAP will make you sick, worried about scopes, worried about having surgery.
- Tired of going to doctors' visits.
- Nervous about having surgery.
- Worried about a family member who is sick from FAP.
- Happy that knowing about FAP will help your doctor keep you healthy!

Lots and lots of people who have FAP are happy and healthy. Sometimes, it can help to know other kids who have FAP. You are NOT alone; there are LOTS of kids who have FAP.

DO I TELL OTHERS THAT I HAVE FAP?

When you first find out that you have FAP, you may find that it is hard to talk about it. You may feel nervous when you talk about it — even with your parents. This is completely normal, but it will help you feel better if you ask questions and share your feelings. Your parents can also set up a time for you to talk with a doctor or a genetic counselor who is used to talking to kids and adults about FAP.

If you want to, you can tell some of your friends about FAP. Talk to your parents first and they will help you decide whom you should tell and what you should tell them. No one can tell that you have FAP by looking at you. However, if you miss school for doctors' visits or for surgery, you may want some of your friends to know the reason. You'll find that having FAP is not so bad after you talk to family members and friends you trust and who care about you.

HOW CAN I CONTACT OTHER KIDS?

You might be the only one at your school or in your town who has FAP. This can sometimes feel very lonely. But there are LOTS of other kids who have FAP!! More than anyone else, they know what it's like to have FAP and what it feels like to thnk you are the only one.

One way to get in touch with other kids with FAP is through support groups. After talking about it with your parents, you can learn more about the groups listed below by sending them a letter or finding them on the Internet. Many libraries have Internet access for people who don't have it at home.

- There is an Internet club for kids with FAP: www.clubs.yahoo.com/clubs/kidswithgardnerssyndrome
- There is also one for parents at: www.clubs.yahoo.com/clubs/gardnerssyndrome
- And one called "Garden Voices" at: www.gardnersyndrome.org

RESOURCES FOR PARENTS

Hereditary Colon Cancer Association
1-800-264-6783
www.hereditarycc.org

IMPACC
Intestinal Multiple Polyposis and Colorectal Cancer
570-788-1818 or
570-788-3712
e-mail: Impacc@epix.net

National Society of Genetic Counselors
610-872-7608
www.nsgc.org/resourcelink.asp

The Collaborative Group of the Americas on Inherited Colorectal Cancer (CGA-ICC) is a group of medical professionals who specialize in hereditary colorectal cancer. Many of these medical professionals work with inherited colorectal cancer registries, which can be an important resource for families with FAP. To locate a registry, go to http://www.geocities.com/cgaicc/institutions.html. Another list of registries can be found at http://www.mdanderson.org/depts/hcc/registries.htm.

WORD LIST

Adenoma: a type of polyp that can turn in to cancer.

Bowel: also called intestine or gut. The bowel is a tube that includes the small intestine, large intestine, and rectum.

Cancer: when cells lose their genetic control, they grow too much, crowd out the cells next to them, and go into parts of the body where they do not belong. Cancer can often be cured if it is found right away. If cancer is not found in time, it will damage the body. Sometimes people die from cancer if the cancer is not stopped soon enough.

Cells: the building blocks of your body. Cells are the smallest living parts of you. Different kinds of cells make up the whole body — skin cells, brain cells, colon cells, and many other kinds.

Chromosome: a long, coiled strand of DNA. People have 46 chromosomes (23 pairs) in each cell of the body.

Colon: a part of the digestive system that removes extra water from the waste in the body.

Colonoscopy: a medical test where a thin tube with a very tiny camera and light (scope) goes into the colon through the rectum. The scope shows the inside of your colon on a TV screen.

DNA: deoxyribonucleic acid. The molecules that contain the genetic code.

Esophagus: the tube that carries food from your mouth down to your stomach.

Familial Adenomatous Polyposis (FAP): a genetic disease that causes polyps to grow in the colon, rectum and other parts of the digestive system.

Gardner syndrome: another name for FAP; Dr. Eldon Gardner wrote about FAP in medical magazines in the 1960s.

Genes: instructions that tell your body how to work.

Genetic Counselor: a person with special training for talking to parents and kids about FAP or other genetic conditions.

Inherited: passed through the family from grandparents, to parents, to their kids.

Large intestine: the colon and the rectum together make up the large intestine.

Mutation: a change in a gene that can make it stop working properly.

Operation: see surgery.

Polyp: a bump or mushroom-shaped growth in the colon.

Rectum: the last few inches of the large intestine, where the stool (poop) is stored before it comes out.

Sigmoidoscopy: like a colonoscopy but it only looks at part of the colon.

Small intestine: the loops of smaller bowel between the stomach and the colon.

Surgery: a specially trained doctor uses his or her hands and special tools to fix, change, or remove something inside the body. Also called an operation.

MATERIALS DEVELOPMENT STATEMENT:

These materials were developed using a health education and a coping and competence framework. This includes an emphasis on learning, problem solving, and building coping skills and is based on research that includes adults and children with chronic health problems. This framework emphasizes being well-informed, goal-setting, defining and understanding problems, making decisions and taking action.

A formal evaluation of FAP & Me demonstrated that children's use of FAP & Me led to an increase in knowledge about FAP and influenced attitudes and interest in practicing health-protective behaviors.

ACKNOWLEDGEMENTS

The authors would like to thank Kate Hibbs, MS[1], Sue V. Petzel, PhD[1], Mary Ahrens, MS[1], and Anna Leininger, MS[2], for conducting an evaluation of FAP & Me; the children and parents from families with FAP who participated in the evaluation; the Hereditary Colon Cancer Association; and numerous medical professionals for their review of this booklet.

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For information about FAP & Me, contact the National Society of Genetic Counselors at fyi@nsgc.org.

FAP & Me is a publication of the National Society of Genetic Counselors, Inc. that was funded by:

NSGC's Audrey Heimler Special Project Fund
March of Dimes
Myriad Genetic Laboratories, Inc.
Minnesota Colorectal Cancer Initiative