

# Kids Familial Adenomatous Polyposis: Introduction

The Hereditary Colorectal Cancer Website has been sponsored by the Robert Rauschenberg Foundation

This section is dedicated to kids and teenagers who have a genetic condition called FAP. FAP, or its full name, familial adenomatous polyposis, is a condition in which polyps (pronounced pol'ips) form in the digestive tract and are inherited. Polyps are abnormal, mushroom-like growths that form on the inside of the digestive tract.

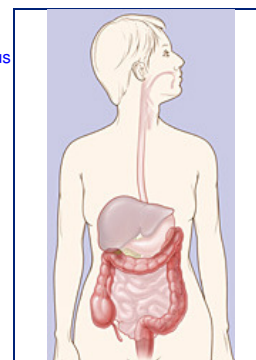


Figure 1. Location of colon in body.

## What is FAP?

Familial adenomatous polyposis, is a condition in which polyps (pronounced pol'ips) form in the digestive tract and are inherited. Polyps are abnormal, mushroom-like growths that form on the inside of the digestive tract.

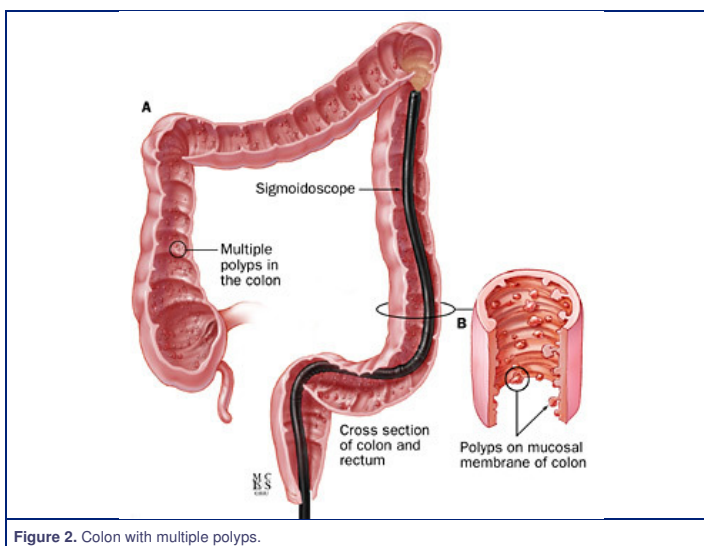


Figure 2. Colon with multiple polyps.

The polyps occur most often in the colon or large intestine. The total length of the colon is approximately 5 feet in the adult and it is responsible for forming, storing, and expelling waste matter.

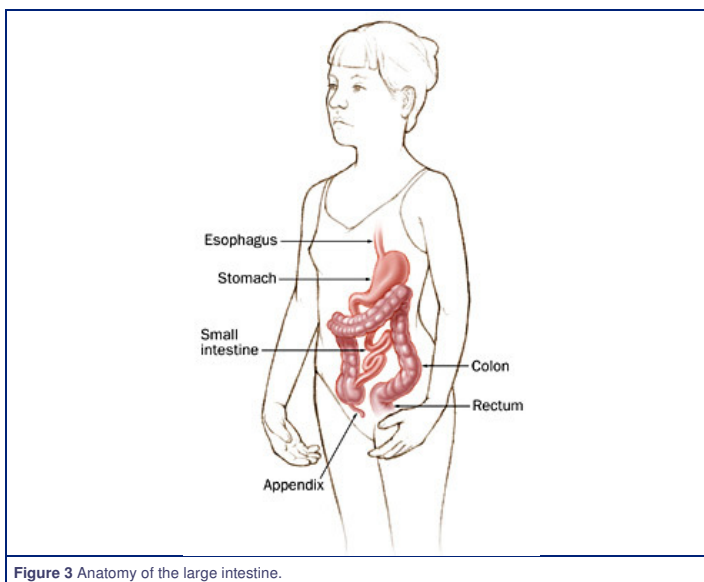


Figure 3 Anatomy of the large intestine.

Polyp sizes vary from the size of a pencil point to the size of a quarter.

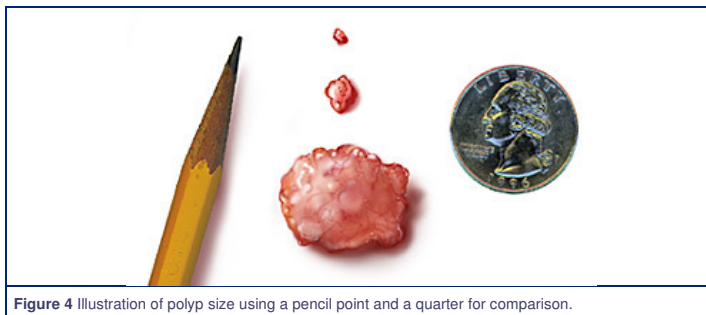


Figure 4 Illustration of polyp size using a pencil point and a quarter for comparison.

Kids with FAP develop hundreds to thousands of polyps throughout the colon at a young age, usually as a teenager or young adult. The major concern about this condition is that the polyps will become cancerous. A person with polyps usually has no idea that the polyps are there.

The most important things to remember are that FAP can be treated and that most kids with FAP lead normal, healthy lives!

### Stories from Kids, Teens and Parents with FAP

The following are stories sent to us from kids, teens, and young adults with FAP. Please feel free to send us a story at [romanka@jhmi.edu](mailto:romanka@jhmi.edu).

#### From Chris, Age 17

My name is Chris and I have been in an FAP study [information on study] for three years. I was 14 when I entered the study. At first I thought it would be neat to be in the study and that it would be a good thing for my future health. Now three years have passed and I am 17. Looking back, I'm not sure I want to be in the study because I am not sure I want to know about "the gene."

I am a normal 17 year-old boy. I get up in the morning, I go to school, and then I go to football, do homework then I go to bed. I liked my life the way it was. It's still the same BUT you have more weight holding you down. You get up sometimes and think, "Did I grow a polyp, did it turn into cancer, am I going to die earlier than most people, am I going to have to go through this my whole life?"

There are some days that I am glad I am doing this. Every time I come out of the doctor's office and he says he did not find anything, what a relief!!! But you need to know that the worry comes back.

If I had to do it all over again I don't know what I would do. It is hard for me to advise other kids because everyone is different. I know that if the parents really care they will let their kids make the decision themselves or at least listen to their children's decisions. It may not be the right one but that's life. There is no way to know if the choice that you make is right, you just have to wait and see.

This part is for the parents of the kids. You can suggest it and list all the good things but you better list the bad things too. You can make the study sound like there is nothing wrong with it, but there is a bad side to everything. You know what they say: "Nothing is perfect."

Back to the kids. I may make the study sound bad but it's not that bad. The only thing that makes it worthwhile is the people who do it. They are the kindest people at the hospital. They do not make you do anything you don't want to. You get a lot of suckers and even some brownies. (Believe me I know.)

Well I suggest that you do go into the study if you want to BUT ONLY IF YOU WANT TO. It is your life not your parents', your friends', or anyone else's. Here are your options, now make the right choice.

#### From Ashley, Age 12

Hi, my name is Ashley. I'll tell you about FAP. I don't like having FAP. I feel alone, left out. It's not fair. My life has changed since I found out I had it. I don't know why I have it, but it stinks! I have my own opinions. You might feel different though. You might be on a study program and take pills like me.

#### From Suzanna, Age 15

When I first found out that I had FAP, I was very upset. I did not want to take medicine and maybe later have colon cancer. After a few trips and quite a few months later, I got used to it all. The doctor and nurses were very nice to me. They made me feel like family and I felt important.

When my family found out that my younger sister had polyps, I was very sad. I wanted to be alone so that I could cry. I would rather had it been me, she's too young. Only 13! I am happy that we went through all that we did.

Although it was hard, I know that we have a future and hopefully can help many other people.

#### From a parent with a child with FAP

Anyone with an ostomy who is willing to share any quick/easy tips they've learned or even show someone how they put their appliance on etc. [would make living with an ostomy] far more relaxing and acceptable. We all know our ostomies act differently at times from food and stress. So anything [anyone can do] to ease the situation or help someone through an embarrassing moment or to help prevent one is welcomed. Once you feel comfortable and your friend understands how you now work you can begin to joke and feel like you fit in.

For those with the section only [the rectum is still intact], I can't stress enough the importance of 3-6 month check-ups and being part of any studies on the subject to find a cure.

#### From an adult with FAP

Being older when I found out I had FAP, my feelings were mixed, but I must say that the biggest feeling I have is THANKFULNESS...

Of course, my original feeling was of SADNESS for my family that they might have to take care of me through the sickness.

When I learned of the operation and the chances of recovery, I became THANKFUL that I could live to take care of them the way I had always hoped.

When I learned, through Johns Hopkins, that I could pass the gene to my children I became SAD again that I could do this to my children.

I learned, again through Johns Hopkins, that there were medications to relieve or eliminate the disease and I agreed to be part of the study to help my children. This made me THANKFUL that I could do something to help them and other families to overcome FAP.

Truly, I am THANKFUL that Johns Hopkins has the doctors, especially Dr. Giardiello, nurses, especially Linda Hyland and the staff, especially Rahj and Kathy, who are

willing to, day after day, perform the "Procedure," study the results...

This makes me THANKFUL that my children and you, as you get older and marry, will be able to have children knowing FAP is being controlled.

I have had the operation and I am THANKFUL that it has not really changed my life, I don't live in pain, I am happy and I hope to live many more years so I can keep pestering Dr. Frank, Linda, and Kathy.

**From Amy**

The other day I had a test, not the normal kind that I would study for. I was given a hospital gown to wear. I laid down on a bed, which was rather comfortable. A nurse put an IV into my arm and took me into a surgery room. I was given medicine to make me sleep. Before they started the procedure, which was very uncomfortable, the doctor took a long tube-shaped object and inserted it into my rectum. It had a light and camera in it. The doctor lasered about three or more polyps out of my colon. I am a little sore from time to time. Polyps are little growths that are in my colon. They can cause a serious disease like cancer. If I were to go untreated, I would get very sick, and could possibly die from colon cancer.

The procedure that deals with the lasering and camera is called endoscopy. If you want my option, it's rather nasty. I have to drink yucky medicine that makes me have loose bowels. Practically my whole family, on my mother's side, has had this disease and many other relatives, including my mom, have had numerous operations.

**Support Groups**

**IMPACC**

Intestinal Multiple Polyposis And Colorectal Cancer

Mrs. Ann Fagan, Administrator

P.O. Box 11

Conyngham, PA 18219

(570) 788-1818 or 788-3712

Fax: (570) 788-4046

E-mail: [Impacc@epix.net](mailto:Impacc@epix.net)

A support group for families with FAP and/or hereditary colorectal cancer.

**UNITED OSTOMY ASSOCIATION, INC.**

National Headquarters

19772 MacArthur Blvd., Suite 200

Irvine, CA 92612

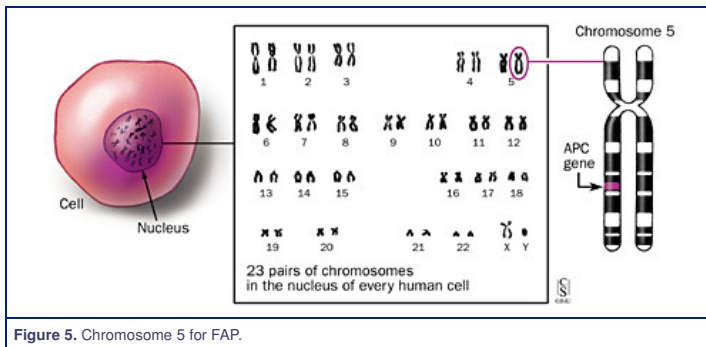
1-800-826-0826

The United Ostomy Association is a national organization of individuals with ostomies who work together for the benefit of all.

# Kids Familial Adenomatous Polyposis: Causes

## What causes FAP?

A gene mutation or change in a gene causes FAP. This gene change can be inherited or passed from a parent to a child. The mutation occurs on chromosome 5.

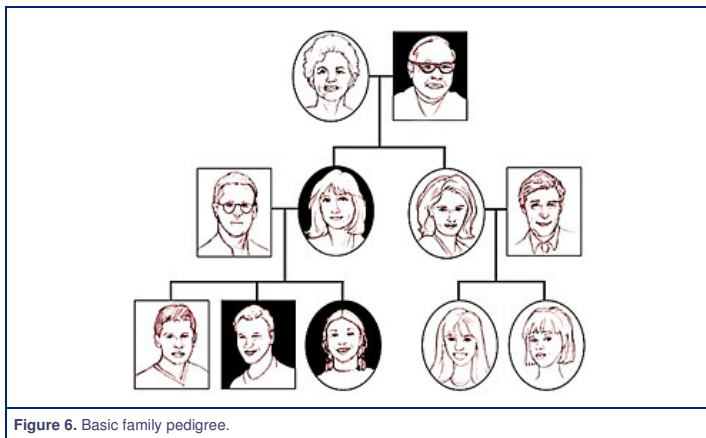


## What do kids do if their parent has FAP?

Kids can inherit FAP from a parent who has this condition. If one of your parents has FAP, you have a 50% chance of also having FAP. Normally kids would go for their first colorectal exam around age 11.

Sometimes genetic testing can be helpful in telling which kids have inherited FAP and which have not.

This family pedigree shows how the grandfather has passed the FAP gene to his daughter. His daughter then passed the FAP gene on to two of her three children.



# Kids Familial Adenomatous Polyposis: Therapy

## **Treatment for FAP**

If polyps are found at examination the doctor will discuss options for treatment. People with FAP will need colorectal surgery after polyps begin to form. People who have their colons removed do live full lives with minor adjustments.