



Editor's note: These responses have not been edited, to retain the voices of the teens who participated in our survey. For each question, the responses appear in random order.

2012 Teen Survey Responses:

1. What do you tell your friends about FA?

- Not much
- I tell them the basics, that I have a rare blood disease called Fanconi anemia, and that it affects the blood cells and certain organs, which causes me to get sick more frequently than others would, and that I go to the hospital more than normal.
- I don't tell my friends
- that I was born with FA, which leads to bone marrow failure.
- That it's genetic and affects the bone marrow. I don't really know exactly how to explain it.
- that it is a rare blood disease
- I tell my friends that I had a serious blood disorder that leads to bone marrow failure.
- I tend to first ask what they know about the bone marrow. After that I try to explain how Fanconi anemia works.
- I tell my friends the truth, so that they can understand. I also tell them to look it up so that they can get more information if they want to.
- I don't tell my friends much about FA. To most of them I'm just a normal kid. My best friend knows a little bit about FA. And my mother is friends with her mother and she talks with her about it.
- When I talk to people about what I've been through, I don't really mention the FA. I got T-Cell ALL Leukemia when I turned 15 (Found out about FA at age 13, but all I really did for that was a few weeks in the hospital and some prednisone, so it wasn't a big deal.) The Leukemia was the big deal, had a Bone Marrow Transplant and lots of complications including fungal infections in the brain and lungs, etc. Transplant was in 2008 so I'm 4 years out and doing well, but FA is in the back of my mind. The BMT treated the Leukemia and the FA.
- Nothing
- That it is a rare genetic disease that causes bone marrow failure and cancer. And that is fatal in every case.

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2. If you have had a transplant, what advice would you offer to other kids who are about to have a transplant?

- To the adults. I had my transplant when I was two so I don't remember it. Which, from everyone else's stories, it's good I don't remember.
- Keep yourself happy; don't focus on the negatives of staying in a hospital. Beyond that, expect the worst, hope for the best.
- Be prepared. It's not easy but eventually you will feel like a normal kid again
- The transplant itself isn't really that bad. All it is is a regular transfusion. In my experience, everything leading up to the transplant was the hard part. The chemo isn't fun but it's not the worst thing. Most important thing is to GET UP and stay active. I had neuropathy in my hands and feet from too much chemo which caused walking to hurt. I stayed bedridden and ended up having to go through a lot of Physical / Occupational Therapy and I doubt I'll ever be able to have the capabilities of a normal person again. (I remain pretty functional but I can't do things like standing for long periods, squatting, etc.) It's just really important to get up even if you don't always feel like it.
- stay strong, fight have the courage and always put on a smile and live day in and day out
- My advice would be to take one day at a time. Take baby steps. Always think positive. And if you are unsure about anything you can always ask your doctor, they are there to help you.
- Don't worry, as best as you can. The docs and nurses are great.

3. If you have had a transplant, how did you connect with friends during transplant and after transplant?

- My class sent cards during transplant. After transplant I jumped back in.
- I was two so I don't remember.
- I had 1 special friend in the hospital who was going through the same transplant as me. We kept each other busy by telling jokes and making special bead keychains that we would hand out to our floor unit. Also staying connected with my family was important. I was able to talk to them on the phone and email them.
- During transplant, the best way I stayed connected was via letters or email. Afterwards, I picked up the pieces of my life that fanconi had blown away.
- At first it was a big decision and I had to choose to have friends or not, yes I was scared and afraid that no one would want to be my friend or understand. It was a big impact on me but once I got out there I had about 10 friends.
- Internet. MSN Instant Messenger. I knew a lot of people from a site I used to frequent that I had added onto MSN. My friends online provided me with something to do and a lot of support.
- I didn't connect with them really. I only talked to my friend once after transplant.

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4. If you could tell your parents exactly what you need from them, what would it be?

- to stop bugging me and let me live my life
- Love, and support, and that they must be there for me.
- For me, my parents treat me how I like it, and there isn't really anything else I could ask for.
- I don't know.
- More money for my life.
- I would tell them that all I needed was what they were giving me already, someone to talk to when I need to and someone to pick me up when I fall, and a shoulder to cry on when I am upset or angry or scared, or just someone to complain to when life just doesn't seem fair.
- I don't need anything from my parents, they give me everything I could possibly need. Along with a lot of support for whatever I want to do.
- I don't know, better genes, I guess?
- To treat me normal
- Umm... I suppose I need their support and also books and chocolate.
- To stop bringing up that I have something wrong with me 24/7
- My mom is great, but my dad doesn't think that I'll get sick again. It would be easier if he did know.

5. If you could tell your siblings exactly what you need from them, what would it be?

- Peace and quiet!
- I don't really need anything from my brothers, because whether they show it or not they give me all the love and support that they can.
- I would like my sister to stop being so mean to me.
- to not be so loud.
- My brother treats me with respect and care any sibling deserves. Nothing could change that.
- I don't need anything from them
- To be there for me always
- Nothing, my sister is amazing.

6. What differences, if any, has FA made in your life?

- not that much
- I get more infections, weekly platelet transfusion, and blood transfusions. Not able to go to school.
- FA has changed my life in so many positive ways. I am able to have a better look out on life and to appreciate it more. I am more positive. I also love to tell others about FA if they ask me.

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- I'm not sure. But I do know that I'm a bit of a "control freak" which probably comes from not being able to control anything or understand what was going on during my transplant. Also, in my mind whenever I'm in any of my "fairy tales" or whatever I'm always running from something or being chained/ locked up, and I have no clue why (in my story). The weird part about it though is that I'm always strong but somehow I'm always caught. In general though it's barely noticeable because I'm really lucky and I look like a normal teenager in high school. Just minus a finger.
- I really don't know.
- I'm closer with my family than most, I've gotten to go places and meet different people, I have lost friends because they didn't know what to do or say around me, but the friends I do have though they are in different states are true and they are there when I need them, I make better and smarter life decisions than most people may have, I have stayed away from drugs and alcohol.
- Other than restrictions in sports at certain points in my life, FA really has made no difference. To people who know me I'm just a normal teenager.
- What in my life hasn't changed because of FA? All my experiences with Fanconi have made me what I am today.
- FA itself didn't really change much. The FA causing the Leukemia is what really caused a lot of trouble. But I've already explained a lot of that. I had to do online schooling for a few years but I still graduated with my class with a 4.0 GPA and got admitted into a private university with Academic Scholarships. Just have to work hard.
- I just have to miss school more for more than the usual number of doctors' appointments.
- It makes me not as good and it doesn't let me live my life the way I want to. I can't drink when I get older, I can't join the Military, I won't be tall like everyone else. It sucks.
- It has made my life different because I know I have something wrong with me and I feel like I never fit in. I also have a deformed thumb and I am never able to show it because it embarrasses me to no end
- It has decided what I want to do with my degree and how I think about issues.

7. What advice would you give someone just diagnosed with FA?

- it'll be ok
- They must be positive, and believe that there will be hope.
- I honestly have no clue.
- that it's not so bad.
- My advice would be to stay strong. Don't give up and keep fighting.
- Accept what you have, keep your chin up and don't let anyone try to tell you you can't do something because of what you have, yes there will be some bad days but the good will outweigh them all.

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- Honestly, that's tough to say. For me, FA was basically nothing. It's not really much to worry about unless it causes something else. The treatment I underwent strictly for FA was very minor and manageable.
- Realize that what you are facing is a deadly disease. But remember that there is always hope, and that you can and will make it through this.
- The advice I would give is to not let it stand in your way of doing what you want to do. Sure you might not be able to do certain things at certain points in your life. But embrace what you can do at that moment in time, and then fight for what you can't have every chance you get.
- You will have struggles but always try and be confident. This is who you are so be proud of it
- Just live as you normally do. Live your life like you don't have FA. You can still have a social life; you don't have to give it up.
- Take a deep breath, get a big hug from a parent or friend. Just keep breathing.

8. What are your fears or concerns about having FA? What do you do to make yourself feel better about these concerns?

- write about it.
- Well I fear dying, so for me to be able to forget about it, I like being around my friends.
- Well, I have no idea how long I might live. I know so many people who have died. Most young, the rest middle life maybe, and a few old. My biggest fear about having FA is that I won't be able to do what I want and live my life. I don't think I'm willing to go through a surgery or treatment that would leave me in the hospital for months. I'd rather be dead at that point. I hate hospitals, I'm afraid of doctors, and I shouldn't be 'cause they've saved my life, but I am. I'm scared at the way they can manipulate your body, all the poking and prodding, and the lack of privacy and your own clothes. You can never get a good sleep where you feel rested afterward. To me Hospital = Pain. The last large checkup I had I was crying and I wanted to hold my dog. But it had to be my dog. I know too much about dogs to be content with just any dog. A dog responds to its owner/ trainer. Service dogs don't look at you, they are always paying attention to their owners. I can see it in their eyes and what I wanted was a dog to pay attention to me. What do I do to make myself feel better? I don't know, nothing really. I guess I just try not to think about it too much.
- I don't like talking about my fears or concerns because that makes it real. I have lost my sister to FA so I already know what my chances are so that is also my fear. I talk with my mom.
- My only concern that still haunts me, even after treatment is, how long do I actually have to live, and will I get cancer? Beyond that, everything that scared me about F.A has gone away due to treatment.
- My fears and concerns are for the future. Since I am 9 years post transplant, there is always something that could turn up. I make myself feel better, I try to stay positive and look at the brighter side of a situation.

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- Talking about fears period. I have a huge fear of death, so with having FA that made it a little worse, being more prone to health issues and such. But then I realized living in constant fear of something will control your life. Then I thought why should I be afraid of something that one day everyone will go through? Although it's still in the back of my head I don't let my fear control me and the things that I do. I live my life the way I want to, not letting my fear get in the way.
- I've been through the worst so there's not much left to fear. I guess I always worry about getting another type of cancer or having the Leukemia come back. But I've been healthy so I don't really think about it. I'm reminded every day of what I went through just from minor physical limitations, though.
- I really don't enjoy the prospect of having all of my hair fall out. But then I tell myself that it'll grow back, and maybe it'll grow in in a different color. That would be fun.
- I want to make it to 50 years. My fear is that I won't make it that long because of FA. I push it out of my mind, I'll do my best. That's all I can do.
- I am always in fear about other conditions I may develop such as cancer or diabetes. I don't do anything to make me feel better cause it won't work
- I just hate it

9. What are some of your favorite ways to relax or have fun?

- Listen to music, watch TV or DVD's, hang out with my friends.
- Every once in a while I hang out with my sixty three year old friend—we like to go to the movies. She's nice but we can only relate to each other to a certain point. I enjoy being by myself with my dogs. It's quiet, and I find my sister noisy and obnoxious and she's never nice to me, even when I'm sick, she says I'm faking it. I haven't really found anything I really enjoy, my mom offers to take me to watch my sister play soccer or basketball. I wouldn't say I hate but I really don't like sports. None of my family enjoys the things I do and I haven't found friends that do either. So, my solution has been to find things I can do by myself. I taught myself to juggle—I'm working on four now—bracelet making, crafts, and I just recently learned how to solve a rubix cube. I enjoy reading.
- playing xbox or being with my friends.
- be with my boyfriend or at my job
- Music has been a huge part of my life. I would listen to Bon Jovi in the hospital every day. That is what has kept me going. I also love hanging out with friends and family or reading a book.
- My favorite way to relax is reading and immersing myself in different stories. My favorite way to have fun is hanging with my friends on Xbox Live.
- I like to chat with friends and family. My favorite pastime is a sport called fencing. (I'm deadly with a saber, by the way...) I also greatly enjoy gaming, since I have a decent gaming rig, (A good PC.)
- What I like to do for fun is read, draw, listen to music and play soccer. Hang out with my friends and family. And drive around with nothing to do.

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- Watch TV, Anime, Play Video Games. Talk to people on MSN. Random stuff online. Music. Even if you only do those things you should always have something to do.
- I like to read and watch Howl's Moving Castle. I also like to go outside and hike. I draw a bit. I make jewelry. I also read web comics.
- I love to do tumbling
- Listen to music or hang out with friends
- I like to read and dance.

10. Is there anything else that you would like to share with us?

- I was diagnosed with FA at the age of 1, and have developed AML and aplastic anemia in May 2011.
- I wish I had gloves that fit correctly—for skiing, a leather riding pair, and just something I could keep my hands warm with cut off at the tips so I can use my fingers easy for writing 'cause I'm always cold especially my hands. I'll be wearing pants, long sleeved shirt and a jacket that is normally worn during fall and everyone else will be in tee-shirts and shorts. And I'm not remembering as well as I used to, learning's a lot harder.
- To all the FA teen Xbox Live gamers out there, contact the FARF office (info@fanconi.org) for my online gaming contact and send a friend request or message.
- I would like to say that I am so thankful for being here. I want to say a HUGE thank you to all of my doctors who helped me get better. Without you, I wouldn't be here today.
- Although not many people would be excited to have an illness, I'm glad I do to a certain extent. If I didn't have FA I wouldn't be the person I am today, I wouldn't have met the friends and the FAMily that I have today. FA has shaped me to be a strong individual, who doesn't let anything stand in her way of doing what she wants to do, and keeps fighting for the things I can't do.
- Apparently I'm the only reported case in history of a patient who received T Cell ALL Leukemia from Fanconi anemia. (Usually people get AML). Because of this, and all my complications, I had a case study done on me. I feel a little honored to have set a precedent, even though the combination of events that occurred for me are very unlikely with anyone else, seeing as I'm the only reported case in history thus far. Still, maybe the research will help someone in the distant future.
- I am a completely normal teenage nerd girl, except for the fact that I have to be a little more careful than my friends. I feel completely healthy.
- Having FA aggravates me because I know I will never to be able to do things I have always wanted. I have always wanted to do all star cheerleading but medical expenses are a lot of money so I am not able to pay for all star cheer. However I am happy and I know that I have it a lot better than a lot of other children.
- It really isn't fair and I really hate it. A lot of my friends have died because of FA.